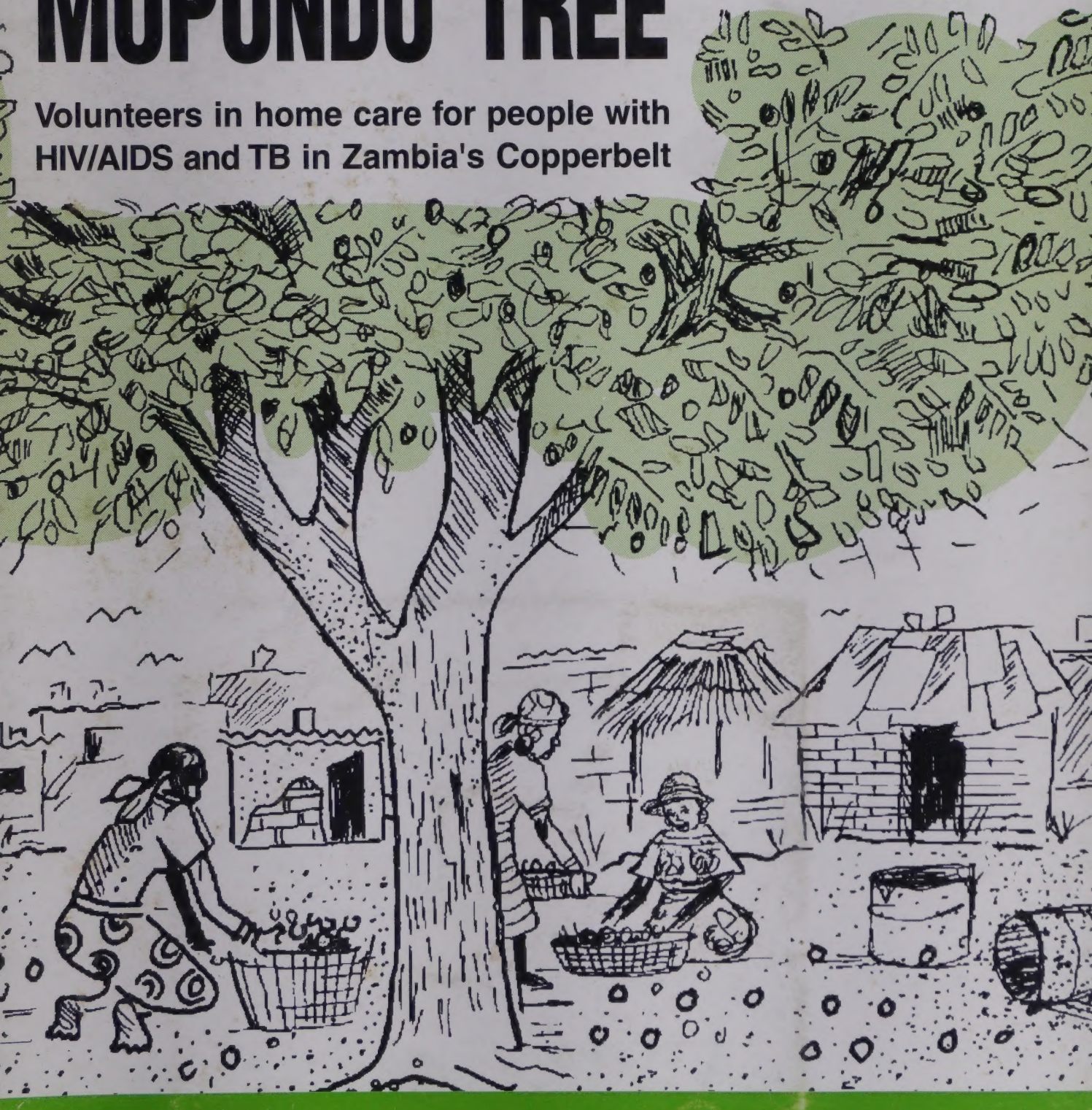
STRATEGIES FOR HOPE No 14

UNDER THE MUPUNDU TREE

Volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt



by Petri Blinkhoff, Esaya Bukanga, Brigitte Syamaleywe and Glen Williams

UNDER THE MUPUNDU TREE

Volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt

by Petri Blinkhoff, Esaya Bukanga, Brigitte Syamalevwe and Glen Williams

ABEKALA MUMUPUNDU EBOMFWA UKO IMPUNDU SHILEPONA.

"Only those under the mupundu tree hear the fruit fall." (Bemba proverb)

STRATEGIES FOR HOPE SERIES
No. 14

Giving People Choices
ACTIONAID

Published by

ACTIONAID, Hamlyn House, Macdonald Road, Archway, London N19 5PG, U.K.

ISBN 1 872502 53 9

First edition, January 1999

The production and distribution of this book have been assisted financially by the consortium of nine European donor agencies which supports the Ndola Catholic Diocese's AIDS programme, and by special grants from Memisa Medicus Mundi, Christian Aid and the Netherlands Embassy, Lusaka.

Photographs: Sr Constantia Treppe (pp. 16, 21, 22, 34, 36, 37, 40, 54), Glen Williams (pp. 3, 4, 12, 19, 27, 44, 46, 52, 55, 57).

Cover and Design: Alison Williams and Alan Hughes

Cover drawing: Danny Chyesu

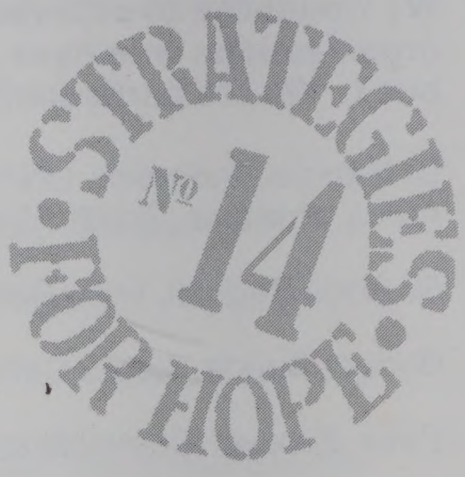
Illustrations: Alan Hughes

Typesetting: Alison Williams

Printed by Parchment Ltd (Oxford).

Edited and produced by G & A Williams, Oxford, U.K.

UNDER THE MUPUNDU TREE



Volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt

CONTENTS

ACKNOWLEDGEMENTS

We would like to express our deep gratitude to the many people and organisations who have assisted us in researching and writing this book. We are particularly indebted to:

Dr Sandra Anderson, UNAIDS Regional Office for Eastern & Southern Africa, Pretoria, South Africa

Sr Anne Bagnell, Holy Rosary Sisters, Ndola

Bridget Banda, Ndola Catholic Diocese, Ndola

Peter Bwalye, Counselling Unit, Kitwe Central Hospital, Kitwe

Dr Clement Chela, Commonwealth Secretariat, London, U.K.

Members of the Chishilano Support Group, Nkwazi township, Ndola

Dr Susan Foster, Department of International Health, Boston University, Boston, USA

Sr Immaculata, Franciscan Missionary Sisters of Service, Mufulira

Emmanuel Kafula, Ipusukilo Development Committee, Ipusukilo

Eunice Kasochi, Pastoral Care Centre, Kitwe Central Hospital, Kitwe

Dr Eileen Keane, Holy Rosary Sisters, Ndola

Evaristo Masongo, Kawama East township, Mufulira

Dr Vainess Mfungwe, TB Coordinator, Ndola Urban Health District, Ndola

Members of the Missionaries of Africa ('White Fathers'), Ndola

Sr Elizabeth Moodie, Sacred Hearts Sisters, Ndola

Dr Cheswa Mporokoso, Kitwe Central Hospital, Kitwe

Ephenia Mukuka, Health Neighbourhood Association, Ipusukilo

Judith Mumbi, Ipusukilo Development Committee, Ipusukilo

Maynard Musonda, Kawama East township, Mufulira

Dr Celestine Nzala, Executive Director, Kitwe Central Hospital

Dr Michael O'Dwyer, Department for International Development (U.K.), Lusaka

Dr Rik Peeperkorn, Royal Netherlands Embassy, Lusaka

Kangwa Samundengu, Ipusukilo Development Committee, Ipusukilo

Dr Moses Sichone, Central Board of Health, Lusaka

Lisa Shone, International Care Relief, Ndola

Dr Eric van Praag, World Health Organization, Geneva, Switzerland

Staff of the Victim Support Unit, Zambian Police, Mufulira

Sr Edith Wood, Sacred Hearts Sisters, Lusaka.

For comments on draft chapters of the book, we would like to express our special thanks to Dr Sandra Anderson, Dr Mazuwa Banda, Dr Jacqueline Bataringaya, Fr Frank Carey, Helen Elsey, Heidi Larson, Chris Mahoney, Dr David Morley, Dr Roland Msiska, Dr Nigel Padfield, Dr Sunanda Ray, Helen Schietinger, Dr Eric van Praag, Jon Twinn, Dr Alice Welbourn, Professor Alan Whiteside and Colin Williams.

We are particularly grateful to Dr Piet Reijer and Dr Dermot Maher for the invaluable technical support and guidance which they have provided during the research and writing of this book.

We would also like to thank the AIDS Department of Ndola Catholic Diocese and the Strategies for Hope Management Committee for their support and practical assistance.

Above all, we would like to express our heartfelt thanks to the volunteers of the Copperbelt home care project and the communities they serve, especially in the townships of Kawama East (Mufulira), Ipusukilo (Kitwe) and Nkwazi (Ndola), for sharing with us their experiences – their joys as well as their problems – and their hopes for the future.

Petri Blinkhoff
Esaya Bukanga
Brigitte Syamalevwe
Glen Williams

1 December 1998

NOTE: The names of people quoted or mentioned in this book have been changed, unless the persons concerned have given permission for their real names to be used.

FOREWORD

Under the Mupundu Tree addresses two epidemics – the dual epidemic of HIV and of tuberculosis (TB). The interaction between TB and HIV is lethal. TB adds to the burden of illness of HIV-infected people and shortens their life expectancy, while HIV spurs the spread of TB. Millions of TB carriers who otherwise would have escaped active TB are now developing the disease because their immune system is under attack from HIV.

Africa, where HIV has spread widely since the late 1970s, already faces a disastrous dual epidemic. TB is the leading cause of death in African people living with HIV/AIDS. In some countries in our region, the numbers of people with TB have doubled or even tripled since 1985. These caseloads are overwhelming health care systems that are stretched to breaking point, especially in these times of economic crisis. Home care becomes both a necessity as well as a choice, but it also raises questions of sustainability, coverage and quality.

This latest book in the Strategies for Hope Series presents a fresh, insightful analysis to inform and stimulate front-line workers, religious organisations, health leaders, policy makers, programme managers and all those who face the challenge of caring during this dual epidemic. We are helped and encouraged to develop sustainable strategies that will yield synergy between TB and HIV programmes, services and care providers – whether in homes, clinics or hospitals.

The book sheds new light on volunteerism, a concept of great importance in many different types of society. The actions of the individual volunteer may seem simple and commonplace, but they are also uniquely precious and noble. They are especially valuable in impoverished communities afflicted by the dual epidemic of HIV and TB, where all available resources – especially the human ones – must be utilised, supported and openly appreciated. In such communities, volunteers may prove to be the only AND the best option available, providing they are linked to support structures within the community, the government and other sections of society.

The generosity of the volunteers in Zambia's Copperbelt, as described in this book, is an inspiration to us all for renewed commitment to meet the great challenges of the dual epidemic of HIV and TB. Once again, the Strategies for Hope Series deserves our thanks and solidarity for their uniquely valuable contribution to our understanding of the challenges we face, and especially for helping us to explore creative and hopeful ways of responding to those challenges.

Elhadj As Sy and Sandra Anderson
UNAIDS Intercountry Team for Eastern and Southern Africa
Pretoria, South Africa

1. Introduction

Two devastating epidemics threaten the lives of tens of millions of people worldwide.

The first of these epidemics is caused by the human immunodeficiency virus (HIV), which leads to AIDS. Already, according to UNAIDS and the World Health Organization, almost 12 million people worldwide have died of HIV/AIDS since the start of the epidemic[1]. Another 31 million people – many chronically ill – are living with the virus. The impact of HIV/AIDS is greatest in sub-Saharan Africa, where 83% of AIDS deaths worldwide have occurred and nearly 21 million people are currently living with HIV.

The second epidemic is caused by the tuberculosis (TB) germ, which already kills 3 million people worldwide annually – more than any other infectious disease. HIV and TB feed off each other, each accelerating the other's progress. Among people living with HIV, TB dramatically reduces the quality of life and shortens survival time. The HIV epidemic, for its part, accelerates the spread of TB and increases its prevalence within the population as a whole.

Africa now faces a devastating dual epidemic of HIV and TB, with Zambia in the frontline of the countries most severely affected. One in five adults in Zambia is infected with HIV, and an estimated 90,000 people develop AIDS every year. Moreover, the number of people in Zambia who fall sick with TB has increased from 7,000 new cases a year in 1984 to over 40,000 a year in 1998.

The 'home care' strategy

Like most other countries in sub-Saharan Africa, Zambia faces the problem of how, with severely limited economic resources, to provide a basic level of care and support to everyone affected by the dual epidemic of HIV and TB. This is one of the most daunting challenges facing governments throughout sub-Saharan Africa.

Yet the challenge has also led to innovative responses. In the late 1980s, Zambia saw the emergence of a new strategy known as home (or 'home-based') care. This strategy was not confined simply to medical treatment and nursing, but took a more comprehensive approach to the needs of individuals, families and communities affected by the HIV epidemic. Until recently, however, home care programmes in Zambia – and in other African countries – had generally achieved only limited coverage and often were relatively expensive to operate.

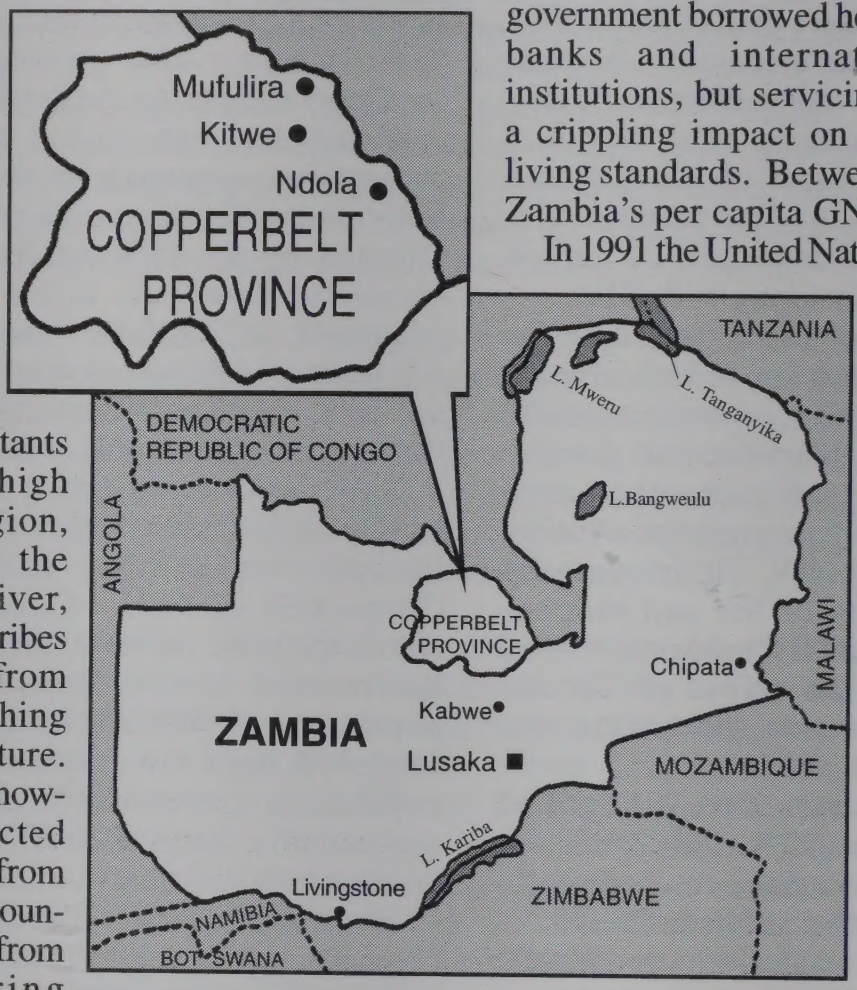
This book is about a home care programme which began in two low-income townships in Zambia's Copperbelt in 1991. Coordinated by Ndola Catholic Diocese, the programme had reached 23 townships with a total population of 400,000 by 1998. It has achieved high coverage of its target population, at reasonable cost, and has successfully integrated TB control into home care activities.

The key to the success of the Copperbelt programme is the role played by over 500 volunteers – mostly women – who assist their neighbours in responding to the daunting challenges of the dual epidemic of HIV and TB. This book describes the work of those volunteers – the people "under the mupundu tree", who understand the problems caused by HIV/AIDS and TB because they encounter them in their own families, and with their neighbours and friends, every day of their lives.

2. Zambia's Copperbelt

Land and people

Zambia's Copperbelt takes its name from one of the world's richest deposits of copper ore, shared with the Katanga region of the Democratic Republic of Congo. Commercial exploitation of the huge copper deposits on the Zambian side of the border started in the mid-1920s. Soon there were six major centres of copper production, extracting the ore through a combination of open cast pits and deep-shaft mining.



The original inhabitants of this high plateau region, drained by the Kafue River, were Bantu tribes who lived from hunting, fishing and agriculture. The mines, however, attracted job-seekers from all over the country, and also from neighbouring countries. Today, the population of Kitwe, Ndola and other urban centres of the Copperbelt is a varied mix of nationalities, cultures, ethnic groups and languages. Population density is relatively high: the Copperbelt is Zambia's smallest but most populous province, accounting for a third of the country's total population of about 9 million.

An economy in crisis

When Zambia achieved independence from Britain in 1964, revenue from copper exports seemed to promise the country a prosperous future. Yet over-reliance on copper, which accounts for 80-90% of Zambia's export revenue, has proved to be the weak point of the country's economy. Economic decline began in the 1970s, with a sharp drop in world copper prices and massive increases in the price of oil. The government borrowed heavily from foreign banks and international financial institutions, but servicing these debts had a crippling impact on the economy and living standards. Between 1976 and 1986, Zambia's per capita GNP fell by 25%.

In 1991 the United National Independence Party, which had ruled Zambia on socialist principles for 27 years, was replaced by the Movement for a Multiparty Democracy. The old regime left behind an economy in crisis, an inefficient state bureaucracy, a huge foreign debt and a health care system near collapse. The new government introduced radical changes, including a conversion to the free market system, privatisation of almost all sectors of the economy, and a process of decentralisation across the public sectors. In addition, the government embarked upon an ambitious programme of expenditure and management reforms in education and the health sector.

The short-term results of these changes have been disappointing, and massive hardship is continuing for millions of people in Zambia. Inflation has pushed up the prices of basic foodstuffs. The

A Copperbelt township: mud brick houses with poor sanitation and lacking safe drinking water.

health status of women is generally poor and many children are malnourished. In the Copperbelt, the privatisation of mines and facilities previously owned by Zambia Consolidated Copper Mines has led to the loss of tens of thousands of jobs. The World Bank has estimated that 69% of the Zambian population live in households that lack sufficient income to meet their basic daily needs.

Social organisation

The Copperbelt is the most urbanised of Zambia's Provinces, with 80% of the population living in seven towns and cities. These generally consist of a city centre with good quality housing, separated by a thin 'green belt' from a ring of townships, or 'compounds', consisting mostly of mud brick houses. The townships, with populations of 10,000 to 40,000 people, were originally begun as illegal settlements and still suffer from a legacy of poor sanitation, lack of safe drinking water and inadequate school facilities.

As in other parts of Zambia, Christian churches play a leading role in community life in the Copperbelt. Most people belong to a church and attendance at services of worship is high. Relations between the various Christian denominations are generally cordial. More than any other social institution in Zambia, churches have the capacity to reach, inform, support and mobilise communities at grassroots level.

3: The dual epidemic and the 'home care gap'

Zambia is experiencing one of the most devastating HIV epidemics in the world. In 1997 the number of people in Zambia infected with HIV was officially estimated at over 1 million – 950,000 adults and 70,000 children – in a total population of 9 million[2].

Most of those now infected with HIV will progress to the advanced stage of HIV disease known as AIDS, and will die within 10-15 years after becoming infected.

Among adults in Zambia the great majority of HIV infections occur through unprotected heterosexual intercourse, with only about 1.5% infected through blood transfusions, contaminated needles or other contact with infected blood. An estimated 25,000 babies each year are infected with HIV through their mothers – either during pregnancy, or at the time of birth, or through breastmilk. A baby born to an HIV-positive woman in Zambia has a 30-40% chance of being infected with HIV[3].

The Zambian Government, the mass media, local and international NGOs, churches, schools, community groups and other organisations have disseminated a great deal of information about HIV and AIDS in the past decade. As a result, most adults and young people in Zambia now know some basic facts about HIV and AIDS, and there are indications that people in some parts of the country may be having fewer casual partners and using condoms more frequently.

Yet there is still a long time lag between changes in public awareness of HIV/AIDS and changes in sexual behaviour. On current trends, HIV prevalence among adults is expected to remain at 19.9% until the year 2000 and then decline gradually to about 16% by the year 2010[4].

Upsurge in TB

As in many other countries of sub-Saharan Africa and in some other parts of the world, the HIV epidemic in Zambia has provoked a massive upsurge in TB. HIV and TB are a lethal combination, each magnifying the impact of the other (see box opposite).

AIDS prevention billboard produced by the Copperbelt Health Education Project.

Ten Facts about TB and HIV

1. Two billion people worldwide – one in three of the world's population – are infected with *Mycobacterium tuberculosis*, the germ that can lead to active tuberculosis. In sub-Saharan Africa and large parts of South Asia, about half the population is infected with the TB germ.

2. Most people infected with the TB germ are not sick and are not infectious to others. Only people who are sick with active pulmonary TB (i.e. TB of the lungs) are infectious. When they cough, sneeze, spit or even talk, they propel TB germs into the air, which can infect other people.

3. Untreated, a person with active TB will infect on average 10-15 people each year.

4. Within one or two weeks of starting TB treatment, people who are sick with TB are generally no longer infectious to others.

5. TB is spreading rapidly. Every year, 7-8 million become sick with TB, and 3 million deaths due to TB occur throughout the world. (By comparison, there were 5.8 million new HIV infections and 2.3 million AIDS deaths worldwide in 1997.)

6. HIV is accelerating the spread of TB by attacking the immune system of people who otherwise would not have developed active TB. People carrying the TB germ are at least ten times more likely to develop active TB, and become sick, if they are also HIV-positive.

7. In several African countries TB cases have doubled or even trebled in the past ten years, due to the HIV epidemic. By the end of the century, HIV will annually cause nearly 1.5 million cases of active TB worldwide that otherwise would not have occurred.

8. TB is the leading cause of death among people who are HIV-positive. It adds to their burden of illness and shortens their life expectancy. Worldwide, TB accounts for nearly one-third of AIDS deaths. In Africa and Asia, it accounts for 40% of AIDS deaths.

9. With TB patients, the risk of dying from TB is at least double among those who are also infected with HIV.

10. Appropriate treatment of HIV-positive TB patients increases survival time by two years on average.

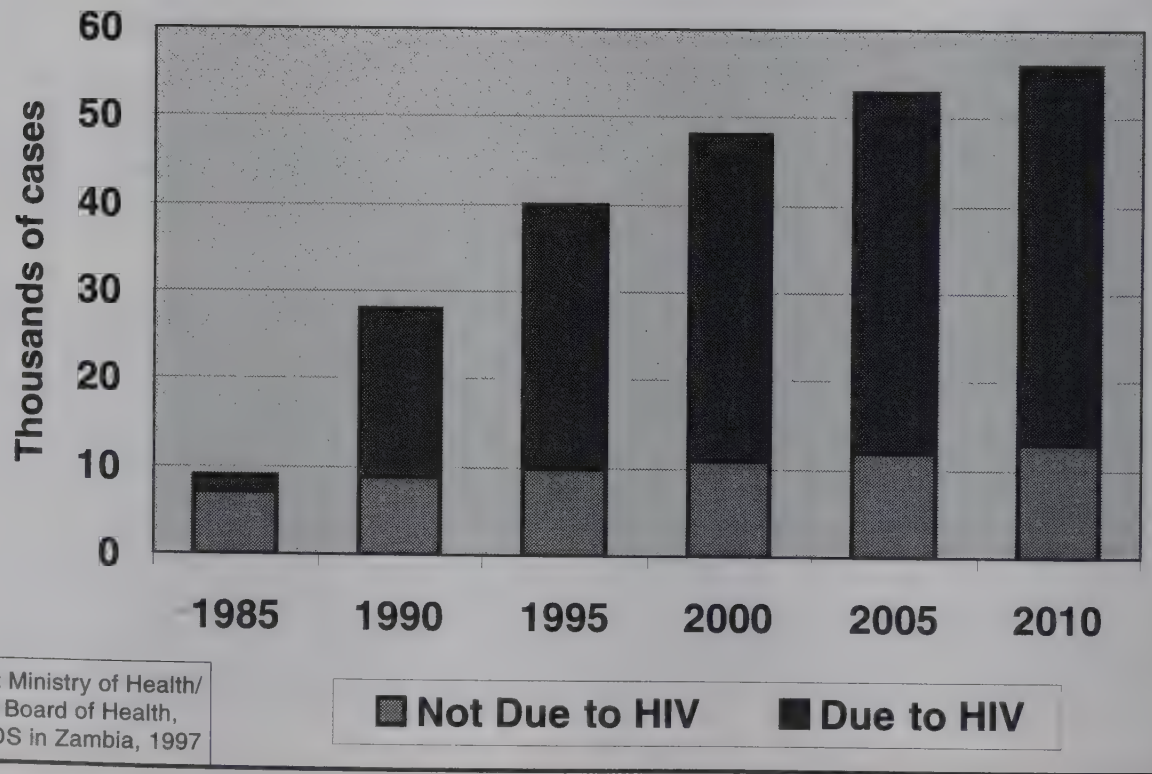
Sources: UNAIDS, *Tuberculosis and AIDS*, October 1997; Raviglione MC et al, "Tuberculosis and HIV: current status in Africa", *AIDS* 1997, 11 (suppl B):S115-S123; Maher D (personal communication), Global Tuberculosis Programme, WHO, Geneva; WHO, "Tuberculosis", Fact Sheet No. 104, February 1998; WHO, *TB/HIV: A Clinical Manual*, 1996.

Between 1964 and 1984 the prevalence of TB in Zambia was roughly stable: in 1984 a total of 7,000 new cases of active TB were reported to the Ministry of Health. By the mid-1990s, however, the situation had changed dramatically, and 40,000 new cases were reported in 1995. Without the HIV epidemic, about 10,000 new cases of TB a year would have been expected in 1995 – the 30,000 additional cases were almost entirely due to HIV. By the year 2005, the additional number of new TB cases due to the HIV epidemic is likely to reach 40,000 per year[5]. (See Figure 1 below.)

Effective therapy for treating TB has been available for the past four decades. Until recently, however, this therapy has required stays of at least two months in hospital, followed by unsupervised self-treatment at home, using medication supplied by the hospital at intervals of a week, a month or even longer, for another six months. As a result, large numbers of TB patients in Zambia – as in many other African countries – failed to complete the full course of treatment, and cure rates were a very low 15-20%. This system also resulted in congested hospital wards and high costs: 80% of the costs of treating TB patients were due to the hospitalisation of patients.

In January 1996 the Ministry of Health introduced a new system for treating people with TB without hospitalisation. Known as Directly Observed Treatment, Short-course, or DOTS (see box opposite), the new strategy, which is promoted internationally by the World Health Organization, relies on health workers or community volunteers to ensure that TB patients complete their course of treatment. The DOTS strategy has brought considerable improvement in TB control in many countries, including Zambia. However, there are still operational problems in different parts of Zambia and completion rates are too low.

Figure 1: Tuberculosis in Zambia: new cases, 1985-2010 (projections)



Source: Ministry of Health/ Central Board of Health, HIV/AIDS in Zambia, 1997

DOTS: a short course in TB control

- DOTS stands for Directly Observed Treatment, Short-course. It is the global strategy recommended by the World Health Organization for the detection and treatment of TB.

- TB patients can be cured with DOTS wherever they live. WHO has set a target cure rate of 85%. In countries with high HIV prevalence, however, cure rates are up to 20% lower because of a correspondingly higher death rate (due mainly to causes other than TB).

- DOTS consists of five main components:

  - Detection of new infectious cases through microscopic examination of sputum
  - A dependable drug supply for an eight-month course of treatment
  - Direct observation of patients taking their medication for at least the first two months of treatment
  - A reliable system for monitoring patient progress
  - Political and financial commitment by governments.

- The DOTS strategy of TB control generally does not require the patient to stay in hospital for treatment.

- There are six basic anti-TB drugs: isoniazid, rifampicin, pyrazinamide, streptomycin, ethambutol and thiacetazone. The formulations and combinations of these drugs vary from country to country. *Note: WHO recommends that thiacetazone should not be used in people known or suspected to be infected with HIV.*

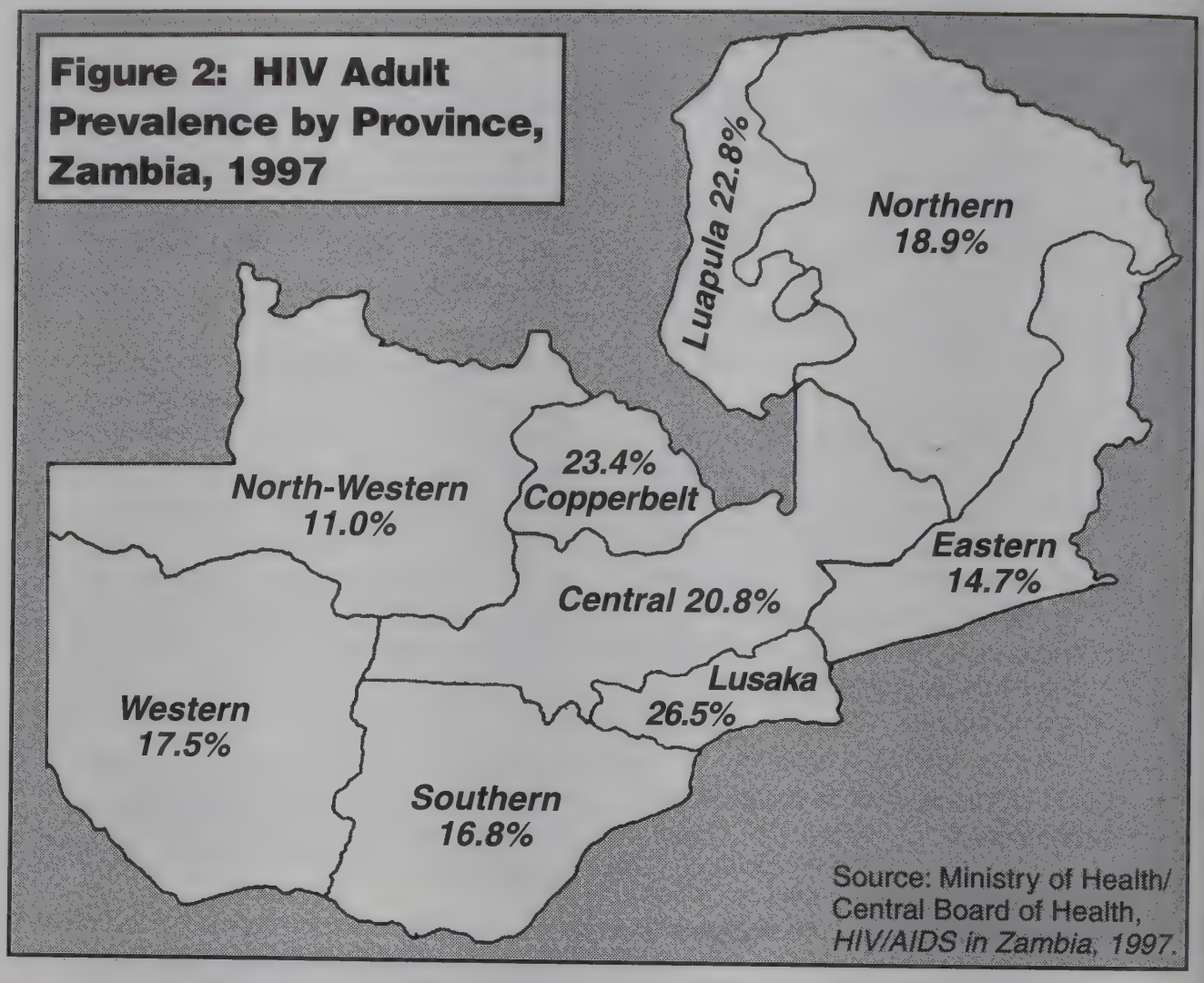
- The cost of a DOTS course of treatment in sub-Saharan Africa ranges between US$15 and US$30.

- The World Bank ranks TB control through DOTS among the top ten public health interventions in terms of cost-effectiveness.

- 95 countries (out of 212 worldwide) have adopted DOTS, of which 63 are implementing the strategy countrywide.

- Worldwide, only about 12% of all TB patients were being treated with DOTS in 1996.

Sources: "DOTS: a breakthrough in TB control", *World Health*, March-April 1998; WHO, "Tuberculosis", Fact Sheet No. 104, February 1998; Grange JM and Zumla A, "Establishing a united front against the injustice of tuberculosis", *International Journal of Tuberculosis and Lung Disease*, Vol. 2, No. 3, March 1998; UNAIDS, *Tuberculosis and AIDS*, October 1997; Harries AD and Maher D, *TB/HIV: A Clinical Manual*, WHO, 1996.



Dimensions of the HIV/AIDS epidemic

On average, one in every five adult Zambians is infected with HIV, but the epidemic is distributed unevenly throughout the country. HIV prevalence in towns and cities is twice as high as in rural areas. The Provinces with the highest HIV prevalence are Lusaka (26.5%), Copperbelt (23.4%) and Central (20.8%). (See Figure 2 above.)

By July 1997 a total of 45,000 cases of AIDS had been reported to the Ministry of Health since the first case in 1984. The Zambian Government acknowledges, however, that most AIDS cases are not officially reported. The true number of cumulative AIDS cases in Zambia is officially estimated at over 400,000, of whom more than half have already died. By the year 2000, the cumulative total of AIDS cases in Zambia will probably reach 700,000[6].

As elsewhere in sub-Saharan Africa, equal numbers of women and men become infected with HIV, but women are affected at a younger age: Zambian women aged 15 to 19 are five times more likely to be infected with HIV than men of the same age. This pattern of infection reflects prevailing attitudes and behaviour in Zambian society, in which it is common for men to be considerably older than their female sexual partners.

Impact of HIV/AIDS

Families: AIDS strikes down people in the prime of life: 84% of Zambians diagnosed as having AIDS are aged between 20 and 39, most of whom are economically active and have young children to support. For individual

families, HIV/AIDS is not only a disease with fatal consequences but an economic disaster. In addition, individuals and families affected by HIV/AIDS often experience discrimination and social isolation due to the stigma attached to the disease.

When one or more family members are suffering an HIV-related illness, expenditure on medical treatment, drugs and traditional remedies rises dramatically. At the same time, loss of labour due to illness or death means that the family receives less food from the farm or cash income from wages. Average households are reduced to poverty and the poor to complete destitution, lacking not only food but basic commodities such as soap, clothes, bed sheets and blankets. Children, especially girls, leave school to help care for younger siblings or sick parents, or to earn money – for example, by selling sex.

Women are particularly disadvantaged. The main burden of caring for sick members of the family usually falls to the wife, mother, grandmother or daughters. This in turn reduces the amount of time a woman has available for earning income and looking after other members of the family. The physical and emotional stress on women in such situations is enormous. After the death of her husband, a widow – who herself may be chronically ill – faces the prospect of raising her children with little or no income, and even without the family house and possessions, as these may be confiscated by the husband's relatives.

Orphans: One of the most serious consequences of the HIV epidemic in Zambia is a dramatic increase in the number of orphans. Between 1990 and 1995 the number of children who had lost either their mother or both parents rose from 20,000 to 200,000; by the year 2000 it is expected to reach a total of 500,000[7]. In Copperbelt Province, the AIDS Department of Ndola Catholic Diocese estimates that about one third of all households are looking after at least one orphaned child, and that over 90% of these children are economically deprived.

The wider economy: The impact of the HIV epidemic on the country's economy is also considerable. The productivity of mines, factories, farms and other enterprises is affected by the loss of skilled labour through premature deaths, and also by the loss of working time through illness and attendance at funerals of family members, friends and colleagues.

Health services: The dual epidemic of HIV and TB has placed health services in Zambia under extreme stress. The burden of providing medical care for people with HIV/AIDS falls mainly on hospitals, where 90% of total expenditure on HIV/AIDS care is incurred. In major hospitals, 50-70% of admissions to medical wards are HIV-positive patients.

The need for HIV test kits, laboratory reagents, diagnostic equipment such as X-ray films, anti-TB drugs and medication for a range of HIV-related conditions has outstripped hospital budgets, leading to chronic shortages. Health centres lack drugs and diagnostic equipment, so can do little to relieve hospitals of the burden of patient care. The need for HIV/AIDS counselling places heavy demands on nursing and medical staff, who are already overburdened with other responsibilities. These problems are exacerbated by Zambia's economic difficulties. Although government allocations to health care as a proportion of national expenditure more than doubled during the 1990s, the real value of this expenditure was severely eroded by inflation.

Origins of home care

During the late 1980s, Zambian NGOs began to respond to the mounting AIDS crisis by developing home (or 'home-based') care services for people with HIV/AIDS. One of the first was the Salvation Army Hospital at Chikankata in Southern Province, which started its home care

programme in 1987[8]. In the Copperbelt, Ndola Central Hospital established a Home-based Care Unit in 1992. Home care was promoted enthusiastically by the Churches Medical Association of Zambia and endorsed by the Ministry of Health. Aided by foreign donor agencies, home care projects were started in different parts of the country. By 1996, the number of home care projects had grown to at least 100, according to the Ministry of Health[9].

The home care approach was also adopted in several other countries in East and Southern Africa, especially by church-related hospitals and NGOs. In Zimbabwe, for example, at least 67 home care projects had been started by 1993. In Uganda, mission hospitals such as Nsambya in Kampala and Kitovu in Masaka developed home care programmes providing thousands of people with HIV/AIDS, and their families, with basic health care and social support.

The first home care programmes in Zambia were developed by hospitals, when the futility of trying to provide hospital-based services to the rapidly growing number of patients with HIV/AIDS was understood. From the outset, exponents of home care took a holistic view of the

Advantages of Home Care

- Good basic care in the home enables the ill person to be as active and productive as possible.
- Family support for the sick person is strengthened.
- Very sick or dying people often prefer to stay at home, especially if they know they cannot be cured in hospital or derive any further benefit from in-patient care.
- Relatives are able to carry out other duties (e.g. work, childcare) more easily if the sick person is at home rather than in hospital.
- Home care can help to relieve the pressure on hospitals, so that staff can give better care to those who really need to be in hospital.
- Home care is usually less expensive for families than hospital care, requiring visits and food to be provided by family members.
- Sometimes hospital care is not possible or is simply unavailable.
- Sick people are comforted by being in their homes and communities with family and friends around.
- Home care can be an effective entry point for support to the survivors of the sick person, especially the widowed spouse and orphaned children.
- Home care offers opportunities for educating families and communities about HIV prevention and can help destigmatise HIV/AIDS and TB.

Sources: WHO/Global Programme on AIDS, *AIDS Home Care Handbook*, 1993; Campbell I and Williams G, *AIDS Management: An Integrated Approach*, Strategies for Hope Series No. 3, 1992; Osborne CM, van Praag E and Jackson H, "Models of care for patients with HIV/AIDS", in: *AIDS 1997*, Vol 11 (suppl B): S135-S141; Gilks C et al, *Sexual Health and Health Care: Care and Support for People with HIV/AIDS in Resource-poor Settings*, Department for International Development, 1998.

problems and needs of HIV-positive people and their families. The activities of home care programmes therefore covered a much wider field than medical and nursing care. Moreover, their focus was not only on the needs of the individual patient, but also on the patient's family and the wider community.

By the early 1990s, home care programmes for people with HIV/AIDS in Zambia usually included most or all of the following activities:

- basic medical and nursing care
- emotional, social and spiritual support to patients and family members
- explaining to family members how to provide HIV/AIDS patients with nursing care within the home
- awareness-raising and education within the family and the community to reduce stigma against people with HIV and to promote behaviour change for HIV prevention.

A number of programmes also provided patients with small amounts of food and other material support. Some had also begun to assist orphans, for example, by paying for schooling and providing food and clothing.

Weaknesses and gaps

Home care proved popular with patients and families in Zambia, and also achieved international recognition. A study of four hospital-based home care projects in Zambia in 1993 by WHO's Global Programme on AIDS and the Zambian Ministry of Health found that almost 90% of patients and their families preferred home care to hospital care. The report concluded that home care programmes in Zambia had been "models and inspiration to the rest of the developing world and have clearly brought immeasurable comfort and service to thousands of people with AIDS, their families and communities"[10].

However, the home care strategy was not without its weaknesses and shortcomings. The first home care programmes in Zambia were carried out by hospital staff travelling directly to patients' homes. This was a time-consuming and expensive process, especially in rural areas, where staff would often spend 75% of their working time on the road and could visit a maximum of eight patients a day. Moreover, travel costs were high, in some cases absorbing more than 40% of project expenditure[11]. The WHO-sponsored study in 1993 found that the average cost of a home visit by a three-person team was US$26, and concluded that home care was "a rather costly, capital intensive service with opportunities to become more efficient"[12].

Recognising these problems, hospital-based home care programmes had already begun in the early 1990s to work more closely with health centres, community organisations and local volunteers. This helped to increase their coverage and reduce their costs. Institutions other than hospitals, such as the Family Health Trust in Lusaka, also started home care programmes. These 'community-based' forms of home care, which involved local volunteers in home visits, were more cost-effective than hospital-based outreach programmes. Moreover, community-based teams were able to spend more time with patients than hospital-based teams[13].

Despite these achievements, home care programmes were still unable to reach more than a small proportion of HIV/AIDS patients in need of care and support. The WHO/Ministry of Health study in 1993 estimated that the proportion of patients receiving home care services was between 5% and 20% of the total number in need of care and support[14].

Volunteers and the dual epidemic

Zambia was not alone in experiencing a 'home care gap': this was the case in all African countries where such projects were in operation. In early 1994, the Southern

A volunteer visits a TB patient: home care programmes for people with HIV/AIDS can also serve as an effective entry point for TB control using the DOTS strategy.

African Network of AIDS Service Organisations (SANASO) organised an international meeting on home care at Chikankata Hospital in Southern Zambia. Representatives from eight Southern African countries concluded that the only realistic means of closing the huge and widening 'home care gap' was greatly increased community involvement. This would require, above all, the mobilisation of many more community-based volunteers from churches and other social groups, such as youth organisations[15].

In the past, many organisations in sub-Saharan Africa have found it extremely difficult to sustain the motivation and active participation of volunteers in primary health care programmes. Yet this does not necessarily mean that efforts to promote the role of volunteers in home care for people with HIV/AIDS in sub-Saharan Africa are doomed to failure.

This book presents evidence from a programme in Zambia's Copperbelt Province that community volunteers, properly trained and well supported, can play a leading role in closing the 'home care gap'. Moreover, this case study demonstrates how home care for people with HIV/AIDS can also serve as an effective entry point for community-based TB control. Just as the dual epidemics of HIV and TB feed off each other, so the strategies for coping with these epidemics can have an extremely powerful, mutually reinforcing effect.

4. Ndola Catholic Diocese: supporting and enabling communities

Early evening in a township on the northern edge of the city of Kitwe. A group of church and community leaders are holding a special meeting in the office of the local Catholic priest. The mood is sombre. There is only one item on the agenda: the large numbers of chronically ill people in the township, due to the rapid spread of TB and HIV/AIDS in recent years.

Some people at the meeting have heard that Ndola Catholic Diocese has helped other neighbouring townships to start home care programmes for chronically sick people. Perhaps the Diocese would help here too? After some discussion the meeting decides to ask the Diocese for help. A letter is later drafted and signed by the Catholic and Anglican Parish priests, ministers from three other churches, the clinical officer from the local health centre, and several prominent local community leaders.

Letters of this kind have been arriving with increasing frequency at the AIDS Department of Ndola Catholic Diocese, which covers not only the city of Ndola, but the whole of Copperbelt Province. Frequent requests for other kinds of help also arrive: school fees and food for the rapidly escalating numbers of orphans, booklets and leaflets about AIDS, and talks or drama presentations about AIDS at schools, churches and community groups. The AIDS Department responds as best it can, with limited resources, to these requests. Half its annual budget is devoted to HIV prevention activities throughout the Province, and the other half to support a home care programme in 23 townships with a total population of 400,000 people.

Origins

The home care programme began in 1991 in two low-income townships on the outskirts of Ndola. Sisters from a Catholic religious congregation, the Sisters of the Sacred Hearts, had set up a small clinic in the office of the local Catholic Church. They soon realized, however, that many chronically ill people were unable to walk to the clinic and would have to be visited at home. This was a laborious, time-consuming job, which could be done only if local people were willing to become involved as volunteer health workers. Christian groups in Zambia have a long tradition of visiting the sick to provide emotional and spiritual support. However, given the negative public attitudes towards people with HIV/AIDS and TB at the time, it was by no means certain that many volunteers for this kind of work would be willing to come forward.

The Sisters approached all the churches in the two townships, asking for volunteers to visit the sick in their homes. The response was enthusiastic, and within three months the Sisters had trained a total of 45 volunteers from the two townships. This was the start of community-based home care for people with HIV and TB in Copperbelt Province.

Programme aims and management

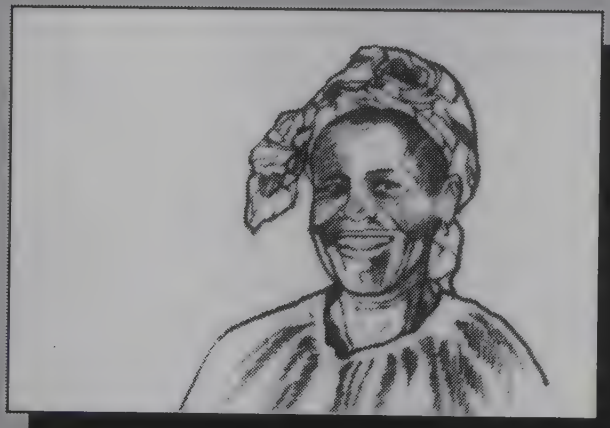
In 1993, Ndola Catholic Diocese established an AIDS Department, in which home care was a high priority. The aims of the home care programme were defined as:

- provision of integrated care for people living with HIV/AIDS
- promotion of awareness concerning the prevention and control of HIV infection and AIDS
- community development.

The number of chronically ill people wishing to join the programme soon increased rapidly. By August 1998, over

Pauline

"The first thing I do each morning," says Pauline, "is pray to God to give me strength for my daily work. Then I do my housework, and after that I go and visit my patients. I look at their medicines and check that they are taking the right amounts at the right times. If necessary I do some cleaning around their houses too."



Forty-six year-old Pauline lives in a low-income township on the outskirts of Ndola, and works as a volunteer with the home care programme coordinated by Ndola Catholic Diocese.

"I was trained to do this work in 1991. I volunteered for it because I felt a call from God, and also because I have a disabled daughter myself. There are five volunteers in our section. We go out together but visit the patients alone because some things are confidential. Sometimes we make 50 visits in a week. In the evenings we do reports. We list the patients who should be visited next and make a programme to visit them.

"People in the community know I do this kind of work. Sometimes when I'm attending to a patient someone will just come and ask me to visit a family member. So I go and visit them straight away. But I don't register them then. First I examine them according to the chart we have and find out their condition. After two or three visits, if the patient seems to be chronically ill, I give the name to the nurse and ask her to make a visit.

"Those patients who are not critically ill I visit once a week. But for those in a critical state, it's every day. Every Monday afternoon we give reports on each patient to the nurses so they can decide who they need to visit. Those who are able to walk come to the clinic here on Wednesday. Those who are in a critical state are visited at home by the nurses during the week.

"When we visit a patient and find they are coughing we take them bottles to collect sputum, and a man on a motorbike comes and takes the sputum to hospital for testing. When the results are back I sit with the patient and the nurse, and she tells the patient they have TB, and I will be supervising them when they take their medicine every morning. I have to watch them take the medicine with water.

"When I am looking after a patient I try to help that person and give them comfort so they can feel happy despite their sickness. They are glad to see us whenever we visit. We also explain to other family members how to look after the patients, and how to protect themselves from getting TB. If the patient is coughing up sputum they should put it in a tin and cover it up. We also explain to them about HIV and AIDS.

"When a patient gets better I feel very happy because I know my work has been worthwhile. If a patient dies I feel very sad because I've built up a relationship with that person. I feel I have really lost someone, and I feel bereaved."

5,500 patients were registered with the programme, and well over 10,000 patients had received assistance from the programme during the previous five years.

The AIDS Department is responsible for the overall policy of the programme, procurement of supplies (drugs, food etc), supervision of local management teams, seeking and reporting on the use of funds, and monitoring and evaluation of programme activities. The Department employs only six full-time staff, including one doctor and one clinical officer, at its head office in Ndola. A total of 28 nurses work in the 23 compounds where the programme operates: 18 nurses are employed by the AIDS Department and 10 are seconded to the programme by District Health Management Teams.

The home care programme does not operate from a hospital or other health institution, but works as a partnership involving various departments of Ndola Catholic Diocese, local NGOs and community groups, District Health Management Teams, government and private hospitals, the Victim Support Unit of the Zambian Police, the World Food Programme, a small number of local businesses and individual well-wishers. The programme is funded mainly by grants from a consortium of European donor organisations*.

At community level, activities are implemented by over 500 volunteers, most of whom have formed their own committees to regulate their affairs. The volunteers in turn are coordinated and supervised by 'managing agencies', who are also responsible for the management of drugs, food and other supplies, and the disbursement of funds. Most managing agencies are congregations of Catholic sisters, one is an order of Catholic priests, and one is a township Development Committee. Managing agencies, in collaboration with local volunteer committees, have considerable flexibility in the organisation of activities at community level.

General approach

The AIDS Department of Ndola Catholic Diocese defines home care as the day-to-day care and support which a chronically ill person receives within the community, either from family members, neighbours or agencies from outside the community. Home care can take the form of medical and nursing care, material and practical assistance, as well as emotional, social and spiritual support. Most chronically ill people are already receiving some form of home care – however limited – from family members, neighbours or friends. A growing number of chronically ill people, however, are abandoned by their families and are completely destitute. The home care programme aims, therefore, to strengthen the capacity of the family and the community to take care of chronically ill people, especially those with HIV or TB.

The programme focuses on people – almost exclusively adults – who have been ill for at least one month, most of whom have symptoms of HIV/AIDS or TB. Those wanting to register with the programme are not required to take an HIV test: indeed, only a small proportion (probably less than 25%) of people registered with the programme have been tested for HIV.

The impact of the HIV epidemic is most severe on people and families living on or below the poverty line. The home care programme is concentrated, therefore, on

* The Consortium members consist of: Action of the Three Kings, Aachen; CAFOD; Caritas Germany; Christian Aid; the European Union (DG VIII); Medical Mission Institute, Würzburg (technical support); Memisa Medicus Mundi (lead agency); Misereor-Katholische Zentralstelle für Entwicklungshilfe c.V.; Missio Aachen; Mission München. In addition, the Southern African AIDS Training Programme provides support for training activities.

The Copperbelt home care programme provides support to family care-givers who are looking after chronically ill relatives.

low-income townships on the edges of five towns and cities of Copperbelt Province. The only exception is the suburb of Ndeke, in Ndola, which is a mixture of lower middle class and low-income households.

As the largest Christian denomination in the Copperbelt, the Catholic Church plays a leading role in the home care programme. However, the AIDS Department of Ndola Catholic Diocese actively promotes the involvement of all Christian churches in home care activities, and volunteers from several Protestant denominations* are active in the programme. Church membership or regular attendance at services of worship is not, however, a pre-condition for a person or family to receive assistance from the programmme.

Community involvement

When a community organisation approaches the Diocese with a request for support for home care activities, the AIDS Department asks the community to organise a meeting, which focuses on three main issues:

"What are the problems?"

"What can the community itself do about the problems?"

"How can the Diocesan AIDS programme assist the community?"

A representative from the AIDS Department participates in the meeting,

* These include, for example, the Anglican Church, the Apostolic Church, several Baptist Churches, the Church of Christ, the Lutheran Church, the Methodist Church, the New Apostolic Church, several Pentecostalist Churches, the Salvation Army, the Seventh Day Adventist Church, the United Church of Zambia, and several independent evangelical churches.

which marks the start of a process of sensitisation, leading towards a mutual understanding about the roles and responsibilities of the community on the one hand, and the AIDS Department on the other. "This can be a time-consuming process," says Dr Piet Reijer, Director of the AIDS Department. "The more the community is aware of what is involved, the less time it will take. But if you rush the issue there will be unrealistic expectations on both sides and the programme might be a failure."

In general, community members contribute to the home care programme in the following ways:

Family care-givers: The primary providers of nursing care and practical assistance to chronically ill people within the home are family members, mainly women. The debilitating effects of the dual epidemic of HIV and TB on people's lives, however, make it increasingly difficult for family care-givers to cope. The situation is worsened by falling living standards due to the steady decline of the Zambian economy.

Volunteers: The front-line workers of the programme are volunteers, the great majority of whom are recruited through their churches. Mostly women, they generally receive no regular remuneration and only small material 'incentives' from the programme. In addition, as is customary in most traditional African societies, patients or their families sometimes give the volunteers small, token gifts in cash or kind (e.g. vegetables, fruit, eggs). There is, however, no obligation on members of the community to reward volunteers in any way for their services.

Contributions for welfare assistance: Most families with a chronically ill person make a small contribution towards the cost of food – mealie meal (maize flour), cooking oil, beans or high energy protein supplement – supplied each month by the programme. These contributions, which are about 10% of the retail value of the food provided, are ploughed back into the programme, for instance, to purchase more food for sale or free distribution, to buy umbrellas, shoes and protective clothing for volunteers, to pay for volunteers' or patients' travel costs to hospital, or to assist destitute patients – for example, with blankets, clothing, funeral costs (including coffins) and transport to home villages.

Building materials and labour: Several communities have constructed simple, mud-walled buildings as meeting places for the programme, using local building materials and voluntary labour.

Material assistance: Some churches, neighbours and relatives provide chronically ill people and their families with food, clothing and money (e.g. for house rent). These contributions are not part of the home care programme as such, but they are an extremely important part of the community response to the HIV and TB epidemics.

Orphan support: Relatives or neighbours support children whose parents have died of AIDS, either by taking them into their own families, or (in the case of households headed by teenagers) assisting them in practical ways.

Programme components

The programme takes a comprehensive approach to the needs and problems of people with HIV or TB, and their families. Its main components are as follows:

Welfare support: The largest single item in the AIDS Department's home care budget is welfare support, not just for the sick person but for other family members as well. The main form of welfare support is food – mealie meal, high energy protein supplement, beans, cooking oil and salt – for which most families make a small cash contribution. TB patients, families with

Sandra

Diagnosed HIV-positive in 1995, Sandra is one of the most active volunteer health workers in Kawama East township, near the mining town of Mufulira.

"My late husband had a degree in Civil Engineering and he worked for the City Council. But he was a heavy drinker and a womaniser. He died in 1992 and was buried two weeks before the birth of my last child, a baby girl.

"After the delivery I developed abdominal pains, chest pains, and herpes zoster on my body. This worried me and I went to ask the nurses at the home care project whether these might be signs of AIDS. Their counselling was very good, and they asked me how prepared I would be if I was told I was HIV-positive. I convinced them that I wanted to know so I could stop worrying.

"So after a blood test they told me I was HIV-positive. I didn't have any problem about accepting it. All I regretted was that I had trusted my husband. My children know that I have HIV. I've been open with them about my marriage, and I encourage them to abstain from sex and concentrate on school."

Sandra now visits four chronically ill people, three of whom are taking medication for TB. She knows that her HIV-positive status makes her more susceptible to TB:

"I know I have to be very careful with TB patients, but I'm a volunteer and it's my job to help them. I feel I have to do it. But since I accepted my HIV-positive status my health has improved a lot. Whenever I notice any small sign of illness I seek treatment straight away – I would never have done that before.

"I live positively with the support I receive from the Sisters, who trained me in tailoring and design. I'm now supervising a tailoring school for young women at our Church.

"I like my voluntary health work because I am able to reassure some of the patients who find it difficult to accept their HIV-positive status. I share my personal experience that denying your status doesn't help to prepare your mind, your body or your soul to live with the virus. But accepting your status will help you to feel more responsible for your own health.

"There's an elder in our Church who wants to marry me, although he knows my HIV status. He has three children and I have five, so we don't need any more. We need to think of the ones we already have and prepare them for the future. We have two options – to abstain or to use condoms."

orphans, and patients who are destitute and abandoned receive food free of charge. The programme also supplies very poor families with basic items such as soap, washing powder, blankets, bed sheets and clothes, and in some cases pays house rent.

The programme provides welfare support to well over half of the approximately 5,500 people currently on the home care register. Most chronically ill people, however, are in need of such support. The decision on whether or not

to assist a particular patient and his or her family – and whether they should make a cash contribution – is made by community volunteers, in collaboration with the nurses working in the local programme.

Medical care: Patients are treated by a community nurse, either at home or by coming to a 'community clinic'. In most townships involved in the programme, nurses hold a clinic in a special building or outside the home of a volunteer in the morning, and visit patients at their homes in the afternoons.

The AIDS Department supplies nurses with a comprehensive package of 40 drugs including, for example, antibiotics, anti-fungal preparations, anti-malarials and pain-killing drugs; also included are vitamin and mineral supplements, and medical supplies such as bandages, gauze and latex gloves. The nurses are generally able to treat common HIV-related conditions such as diarrhoea, cough, skin conditions, oral thrush, ulcers and herpes zoster, and also common sexually transmitted infections. All medical care and drugs are provided free of charge, the costs being covered by the programme's donor agencies.

Patients requiring more specialised medical services are referred to hospitals, with a letter from the nurse. Four of the five hospitals in the Province provide free diagnosis and treatment to outpatients who come with a letter of referral from a nurse from the home care programme. Treatment for TB is carried out according to the DOTS strategy promoted by the World Health Organization (see page 7), using drugs supplied by the District Health authorities.

Nursing care: With good nursing care, chronically ill people living at home can have a reasonably good quality of life.

A nurse meets a patient at a 'community clinic' outside the home of a volunteer.

Ipusukilo township: care in a continuum

Ipusukilo is one of 12 townships on the ragged edges of Kitwe, where the Ndola Catholic Diocese is supporting community-based home care and TB control. The programme began in 1993, on the initiative of the local Development Committee.

Every morning, five days a week, two nurses hold a clinic in the home or the yard of a health volunteer, moving from one neighbourhood to another each day. In the afternoons the nurses, accompanied by volunteers, carry out home visits to patients who are unable to walk to the clinic. This system enables the nurses to have about 600 one-to-one patient consultations each month.

By April 1998, a total of 750 patients and their families had received care and support from the programme: 410 people were still on the register, 300 had died, and 40 had either moved out of the township or left the programme for other reasons.

The home care programme is not a substitute for government health facilities. Rather, it is part of a 'continuum of care' starting with 22 community volunteers and the two nurses, extending to the local health centre, and also involving Kitwe Central Hospital and the District Health Management Team. Whenever the need arises, the home care programme and the health centre refer patients to each other for diagnosis and treatment. TB detection and treatment is carried out under the supervision of Kitwe Central Hospital, using the DOTS strategy. Local volunteers identify new TB patients and also visit patients to ensure they take their anti-TB drugs; volunteers also act as the link persons between the hospital and the community.

HIV testing is carried out through the hospital's Clinical Pastoral Care Centre, which also coordinates the training of HIV/AIDS counsellors for the whole District. The Centre has trained five volunteers from Ipusukilo as 'support counsellors'.

Volunteers from Ipusukilo and 11 other townships around the city also help to organise a free 'home care clinic' at the hospital every Monday afternoon.

The home care programmes in the 12 townships around Kitwe are helping to relieve staff at Kitwe Central Hospital of some of the pressures affecting their work. Dr Cheswa Mporokoso from the hospital explains:

"Before home care was established, it was hard to discharge a patient because you didn't know if they were going to be looked after at home. So we kept them in longer until we saw they were a bit stronger. But sometimes we had to actually force people to go home. Now it's easier to discharge them knowing that the help will continue when they go home."

They need, however, a regular supply of food and safe drinking water, and may also need help in taking their medication in the correct doses at the right times. Some may have sores that have to be dressed and kept clean. They may also need assistance with bathing, getting dressed and going to the toilet. In addition, especially if bed-ridden, they may have to be turned at regular intervals to avoid developing bed sores. These and other nursing tasks are generally carried out by family members, with guidance and support from the nurses and volunteers. If family members are not present or are

Bed-ridden patients need to be turned regularly to avoid developing bed sores.

themselves chronically ill, however, it falls to the volunteers to carry out these tasks.

Practical help: If family members are unavailable, the volunteers carry out practical tasks such as cleaning the sick person's house and yard, washing clothes and bed sheets, fetching and boiling drinking water, collecting firewood and cooking meals. Volunteers also act as a link between the patient, the home care programme and the hospital. For example, if a patient needs transport to or from hospital, the local volunteer will try to obtain the use of a vehicle from the programme, and usually accompanies the patient to hospital as well. In some places volunteers also help to arrange funerals for patients who have been in their care, if family members are unavailable or unable to do so.

Emotional and spiritual support: Volunteers provide emotional and spiritual support to patients and their families, an experience which can be emotionally very draining for the volunteers themselves. Since they have a Christian background, it is natural for them to draw upon their spiritual resources in doing this work. It is not unusual, for example, for volunteers to pray or to read the Bible with patients and their families.

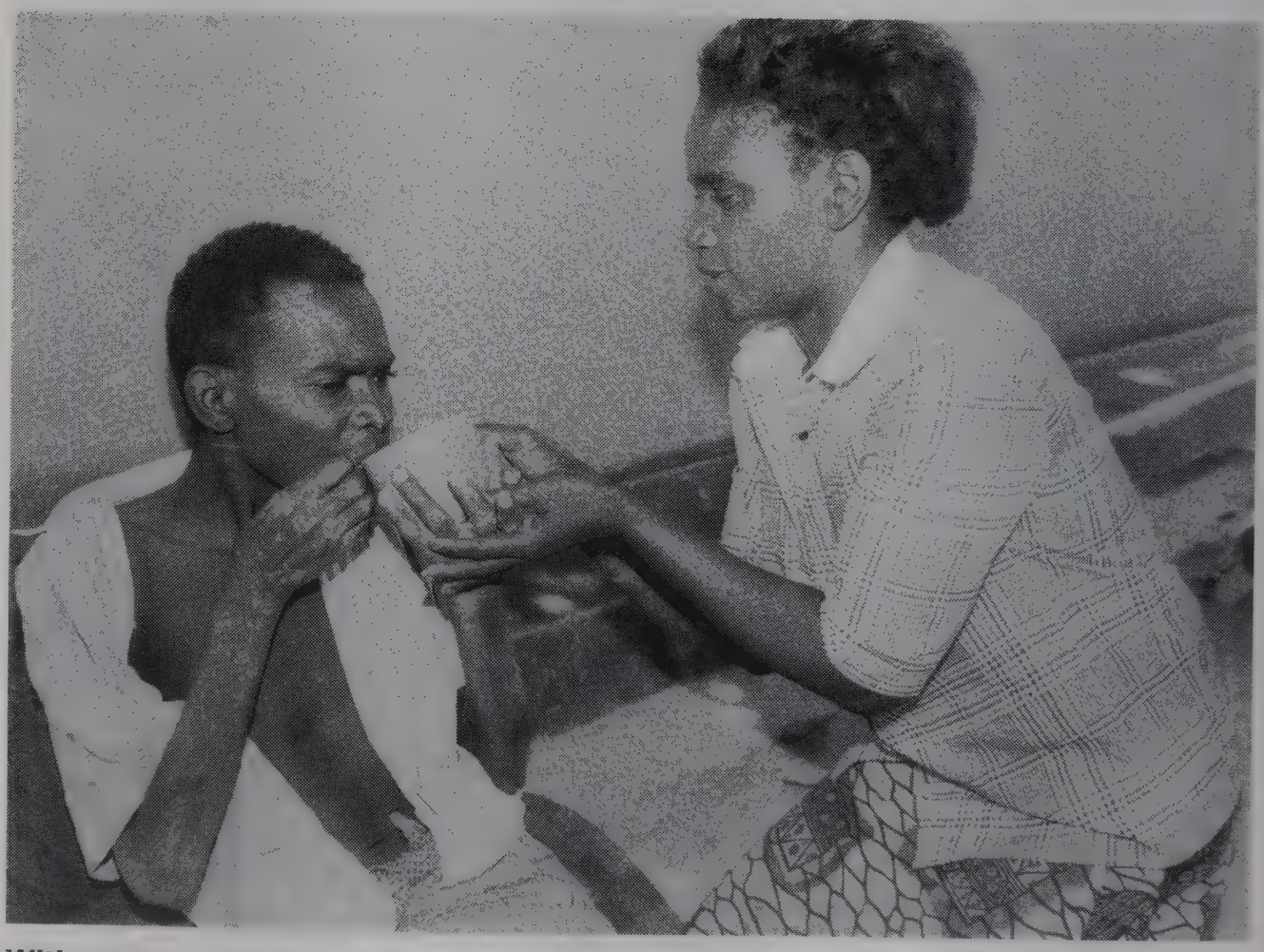
Counselling: Counselling before and after an HIV test is carried out by nurses and also by about 50 volunteers who have received special training. (In principle, HIV testing is done at government hospitals, but at some hospitals shortages of test kits and reagents make this impractical.) Home care nurses and volunteers also offer ongoing counselling to chronically ill people, regardless of whether or not they have had an HIV test.

Information and awareness-raising: Many people are initially reluctant to look after a sick family member because

they are afraid of becoming infected themselves with HIV or TB. Volunteers and nurses give families information about the different ways in which HIV and TB are spread, and correct misconceptions. They help to raise awareness about the need for people living with HIV or TB to feel that they still have the love and support of their families and friends. They also help to reduce the stigmatisation of people with HIV/AIDS or TB, for example, by correcting misinformation and harmful rumours about particular individuals. In addition, community nurses help to educate the public about HIV/AIDS and TB through talks and seminars at churches and other community organisations.

Orphan support: The AIDS Department of Ndola Catholic Diocese supports several thousand orphaned children by paying for food, soap, clothing and schooling. Most of this assistance is channelled through a local NGO, CINDI (Children in Distress). In some townships, however, local volunteers, in collaboration with the community nurses, decide on which families will receive assistance.

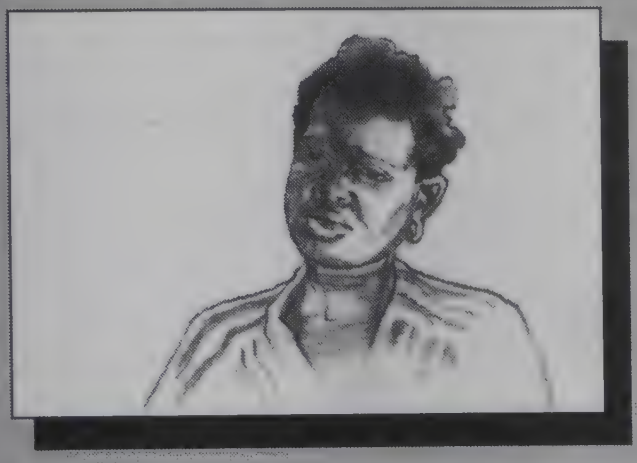
Training in gender and human rights issues: The HIV epidemic has exposed deeply rooted traditional values and practices which help to perpetuate women's dependence on men, and which also create social and economic conditions which favour the spread of HIV. Some traditional practices, such as property grabbing from widows, make women into scapegoats for the HIV epidemic. Through 'training for transformation' workshops, the Development Programme of Ndola



With good nursing care, chronically ill people can have a reasonably good quality of life: safe drinking water is essential.

Margaret

At the age of 20, Margaret is looking after her unemployed husband, their two year-old daughter, three younger brothers and two young cousins. They live in a small mud house in Ipusukilo township, on the banks of the Kafue River.



"My Mum and Dad were divorced in 1993 and the children all stayed with my Mum. But in 1995 she fell ill and died. Our relatives came but they were only interested in grabbing the property. No-one wanted to look after the children. I took them all and came to live here. Then two of my aunts died and their children came here too.

"Some of my cousins are working as house servants in town. They are too young but I couldn't stop them because they need to earn money for food and things. Two of my cousins have had to go out into the street and sell sex. One has been very sick and now has herpes zoster. The other one has a baby who is sick.

"The home care volunteers visit us. They pay the school fees and buy clothes and school equipment for my three brothers. They also bring us food and soap, and sometimes cooking oil. When my aunt died the home care project provided the food, the transport and the coffin for the funeral. I want to sell vegetables in the market, but I need some capital to start.

"Sometimes I wonder about getting divorced. My husband's relatives are not happy about the young orphans that I look after. They think we're spending too much money on them. One day, when only the children were at home, my husband's relatives came to the house and humiliated them. When I came home I found them outside the house, with a note saying I should leave my husband and go and join our mother in her grave. I was crying and so were the children. I went and told Diana*, who is like a mother to me now. I told her what had happened with my husband's relatives, and she encouraged me to ignore them and accept the situation.

"Diana and the home care volunteers have been so helpful to us, but looking after orphans is not easy. Orphans really need help from groups like the home care project. If they don't get help, these children will end up on the street and will become sick. Then the home care project will have to look after them. So I strongly believe that support for orphans is needed to prevent sickness in the future."

* Leader of the home care volunteers in Ipusukilo.

Catholic Diocese helps to empower women so they feel able to challenge harmful values and practices. This type of training is not part of the home care programme as such, but trainers from the Development Programme work closely with home care volunteers, religious leaders and Victim Support Units of the Zambian Police in many parts of the Province (see box, page 24).

Victim Support Unit

In Kawama East, a small township just outside the mining town of Mufulira, the local home care project is helping widows to protect their property. The threat to their property comes, not so much from would-be thieves, but from the relatives of their deceased husbands.

The phenomenon of 'property grabbing' from widows has become widespread in the wake of the HIV epidemic. "To some extent," says Police officer Betty Mchenga, Head of the Victim Support Unit at Mufulira police station, "property grabbing is on the increase because so many people are poor. But most often it's just because the relatives blame the widow for the death of the husband because of witchcraft, or being negligent, or giving him AIDS. So they want to take revenge on her."

The three-person Victim Support Unit was established in Mufulira in March 1997 to provide legal protection against child abuse, violence against women, and property grabbing of widows' inheritances. Betty Mchenga and her colleagues, Sylvester Kapama and Maggie Namwawa, began visiting Kawama East township after attending a workshop on women's inheritance rights organised by the Catholic Diocese in Ndola.

Their meeting place in Kawama East is a small, mud-walled 'shelter' constructed by local people with voluntary labour as the base for their home care project. Every morning, five days a week, two community nurses see chronically ill patients in the main room. In the side room, sitting on the floor, the nurses counsel people about HIV/AIDS and other issues. Here, every Wednesday morning, a police officer from the Victim Support Unit is available to inform women about their inheritance rights and to help them deal with practical problems.

Rosemary Chanda, a 45 year-old widow with two young children, is one of several women in Kawama East who have received help from the Victim Support Unit. After the death of her husband, who worked for the City Council, her husband's relatives obtained the first installment of the 'terminal benefits' paid out by his employer. She went to the home care project, where a nurse put her in touch with the Victim Support Unit. Within a short time the Unit arranged for the funds to be paid to Rosemary. Her husband's relatives are still harrassing her about the balance of the money: they say it belongs to them, but Rosemary says she needs it to look after her children*.

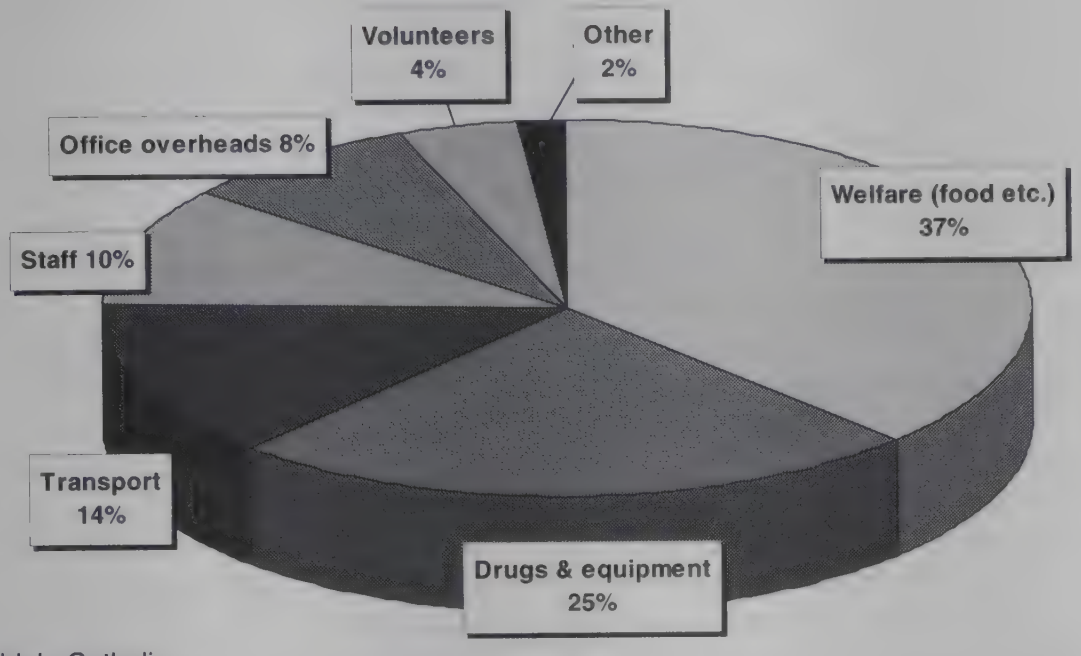
* According to Zambian law, when a person dies without having made a will, his or her property is to be divided up as follows: 50% for children, 20% for the widow, 20% for the deceased's parents, and 10% for dependents.

Coverage

Initially, most patients joined their local home care programme after house-to-house visits by volunteers. As home care became more widely known and accepted, new patients began coming spontaneously to a volunteer, or a family member would ask a volunteer for a community nurse to make a home visit.

The Copperbelt home care programme has achieved very high coverage of chronically ill people in the 23 townships where it operates. A study carried out in the township of Nkwazi, on the outskirts

Figure 3: Ipusukilo home care programme costs, July 1996 – June 1998



Source: Ndola Catholic Diocese, AIDS Department

of Ndola, in early 1998 found that 71% of people who had been sick for at least one month before death during the previous year had been registered with the home care programme[16] *. The average age of death was 33 years – a strong indication that HIV/AIDS was likely to have been the main cause of death.

The study also concluded that this level of coverage is likely to apply in almost all of the 23 townships where the programme operates. Such a high level of coverage suggests that the services provided by the programme are relevant to people's needs, acceptable in terms of quality, easily accessible and affordable to the beneficiaries.

Costs

The costs of the Copperbelt programme are modest in relation to the needs of the beneficiaries. An analysis of programme costs (excluding orphan support) in the township of Ipusukilo over a 24-month period in 1996-98 found that the average expenditure per month was US$2,216 (see Figure 3 above) for about 400 patients – or about 2,500 people when other household members, who also benefit from the programme, are taken into account. The largest single item was welfare support (food, clothing, blankets, bed sheets)** for families, which accounted for 37% of spending, followed by drugs and equipment (25%). The

* Many of those who were not covered by the programme were over 55 years of age – most families do not request outside assistance for this age group. If over-55s are excluded from the study, coverage increases to 78%.

** In addition, most patients or their families made a small contribution towards the cost of food supplements received from the programme. These funds were used to provide volunteers with small travel allowances, to buy protective clothing, and to assist destitute people.

AIDS Department believes that these figures are representative of most of the 23 townships where the home care programme operates.

Another way of expressing the costs of the programme is in terms of the average cost of a nurse consultation, i.e. a one-to-one meeting between a community nurse and a patient, either at a community clinic or through a home visit. In Ipusukilo the average cost of such a consultation during this 24-month period was US$3.00 – US$4.25. This includes not only the cost of food and other welfare support, drugs and equipment, transport and staff salaries, but also office overheads for the AIDS Department, the training of volunteers, home visits for orphan care, and HIV prevention activities such as workshops and other meetings in the community – all of which are integral parts of the programme. If the cost of welfare support is excluded, the average cost of a nurse consultation is reduced to US$1.85 – US$2.60.

These costs cannot be compared to those for hospital care, because home care in the Copperbelt programme consists of a package of services, rather than simply medical and nursing care. Comparisons with other home care programmes are also problematic: a study of the home care programme of Monze District Hospital in 1991, for example, estimated the cost of a home visit at US$14, but this was by a three-person team (social worker, nurse and driver), and did not include food or other welfare support[17].

Home care does involve an opportunity cost, in terms of time spent on nursing care within the home by family members, usually women. The home care programme, however, brings food into the household – either free or at extremely low cost. In addition, the programme often saves the family the considerable cost of hospital treatment, transport costs to and from hospital for the patient and family members, and the cost of food for the patient.

The high coverage and reasonable costs of the programme coordinated by Ndola Catholic Diocese are due in part to its location in high density urban areas. Even more important, however, is the role played by the volunteer health workers in identifying chronically ill people, visiting and supporting patients and their families, and assisting the community nurses in their work. In the next chapter we shall look more closely at how these activities are organised, and how home care can also be an effective entry point for TB control within the community.

5. Nkwazi Township

Josephine is out of breath when she arrives at the small, mud-walled house where Henry sits on the doorstep.

"I'm sorry I'm late," she says. "Have you taken your medicine already?"

"No, not yet," says Henry, with a half-smile. "I was just waiting for you..."

Painfully thin, his eyes sunk deep into their sockets, Henry slowly pulls himself to his feet, assisted by his younger brother. His faded clothes hang loosely from his emaciated limbs as he shuffles into the house, shared with his mother and six younger brothers and sisters.

"How are you feeling today?" Josephine asks.

"Oh, just a little bit OK," he says, but Josephine knows that he is only putting on a brave face. She is a volunteer health worker in Nkwazi township, a low-income neighbourhood on the northern edge of Ndola, the administrative centre and second largest city in Copperbelt Province. She has seen it all before, in other TB patients. At first they seem to be almost at death's door, but after a few months of treatment the improvement is often remarkable, even among those who are HIV-positive. After eight months, with good nursing and a healthy diet, they usually make a complete recovery.

Henry started TB treatment only a fortnight ago. He is still in what is called the 'intensive' phase of treatment. Every morning, at about 7.30 a.m., Josephine comes to check that he takes eight tablets with water, and to give encouragement and advice to him and his family. She gently

The charcoal market in Nkwazi: formerly an illegal settlement, the township is now part of the city of Ndola.

reminds him to turn his head away from other family members when he coughs, and to spit into a tin, which he keeps covered up after use. Sometimes Henry suffers stomach pains after taking the tablets, so she reassures him that this is not unusual and he should keep taking the medication every day.

Josephine will keep visiting Henry every morning for at least two months. When his health improves he will regain his appetite and will need more food, which he can collect at the weekly clinic for TB patients. If he continues to improve, she will visit him only once a week, during the 'continuation' phase of treatment, when his daily drug intake is reduced but he will still need a lot of care and support.

Slow beginnings

An illegal settlement until 1992, Nkwazi is now an officially recognised neighbourhood of 30-40,000 people, with a government health centre and two primary schools. There is also a large market and a number of noisy, well patronised bars. Basic services such as sanitation and drinking water, however, are still very poor.

Nkwazi is one of four low-income townships on the outskirts of Ndola where the Ndola Catholic Diocese supports a home care programme for people who are chronically ill – mostly with HIV or TB, or both. The origins of the programme date back to 1991. A congregation of Catholic nuns, the Sisters of the Sacred Hearts, decided that they had to do something about the rapidly escalating problem of people in the low-income areas around Ndola who were chronically ill, mostly with HIV-related illnesses.

Rather than act simply within the Catholic Church, however, the Sisters recruited volunteers from several local churches. A group of 28 volunteers from Nkwazi were trained over a two-month period, and began to visit families in their neighbourhoods to identify people who had been sick for a month or more. Chronically ill people who agreed to be visited at home by nurses from the Catholic Diocese, accompanied by a volunteer, were registered with the programme.

The home care programme developed slowly at first: by 1992 only 25 patients were registered and visited. "Some people refused to be visited because they were afraid of being stigmatised by their neighbours as AIDS patients," remembers Violet Mukosha, one of the first volunteers to be trained.

In 1993 another 100 patients joined, many of whom had TB as well as HIV/AIDS. To the great dismay of the volunteers, many people with TB died. At this time, TB patients were kept in hospital for at least the first two months of treatment. After discharge they had to take their medicine at home and return to the hospital regularly for fresh supplies and follow-up sputum analysis. Emilia Nkandu, one of the original volunteers, remembers:

"We asked ourselves why so many TB patients were dying, and we realised that they were not taking their medicines. So we thought that if we went to the patients' homes and watched them swallow their medicines, it could help. So that's what we did, and many TB patients were cured after that."

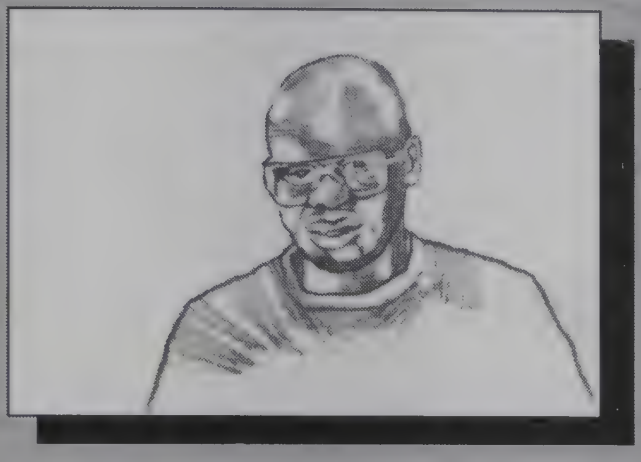
This was not yet the fully developed strategy of TB treatment known as DOTS (Directly Observed Treatment, Short-course) promoted by the World Health Organization, which was introduced into Nkwazi in 1995. It demonstrated, however, that local volunteers have an astute understanding of health behaviour in their own community, and that they are capable of creative responses to their own health problems.

Acceleration

The programme entered a period of accelerated growth in 1994, with the construction of the Chishilano Support

Dominic

A 44 year-old father of eight, Dominic has been a home care volunteer in Nkwazi township since the programme began in 1991:



"I was recruited through my church, the United Church of Zambia. At first there were three men and 51 women volunteers, but one man moved away and the other one dropped out. So now I'm the only man who's a volunteer.

"I work as a road technician for PUSH (Programme for Urban Self Help). I visit patients on Sundays, with the other volunteers from our section. At the moment we have about 32 patients. We each visit about ten patients in a day. If someone is really sick the relatives call for me and I go right away to see them, and arrange for the nurses to visit.

"When we visit a patient we ask how they are feeling. We also talk with the members of the family. Sometimes we find that the relatives are fed up with looking after the patient for such a long time, so we try to give them some encouragement. Some of the relatives want to leave everything to us, like washing the patient's dirty beddings. We explain to them that the patient isn't our relative but theirs. We're only helpers. What does encourage the relatives is when they can get food for the patient. That really motivates them.

"TB patients sometimes give us problems because they don't want to take their medicines. So we have to visit them every day to make sure they do.

"The people in the neighbourhood appreciate our work. Other men used to laugh at me and say I was wasting my time. 'These people have got relatives to look after them,' they would say. I could only reply that I liked the work and found it interesting. Now some other men are interested too, and one wants to become a volunteer. I'm still discussing a few things with him, and the other volunteers in our section also have to agree.

"When I go for a drink with my friends we sometimes talk about AIDS. I tell them that this is the situation we're in and we have to look after ourselves. We have to keep to one partner, we have to use condoms.

"What do I get out of this work? Well, I've learned a lot that can help other people and my own family. Now I know how to tend to my children if they're sick. At Christmas the Sisters arrange a small party and they give us parcels of gifts that we can share with our families. And once a month we can buy a bag of mealie meal from the programme at a cheap price.

"But we don't get any money from the programme. When I first joined it was announced in church that volunteers would not be paid anything. So I never expected any money. But the work has made me known in the community. People recognize me. They know I work in home care."

Centre (see box), which quickly became the focal point for home care, HIV prevention, sexual health and TB control within Nkwazi township.

By August 1998, some 440 people were on the patient register. A total of 1,125 people had been registered with the programme since its inception in 1991: many had since died, some had left the township, and a number of former TB patients had been removed from the register because they no longer needed care and support. (See Figure 4 opposite.)

The Chishilano Centre is the base for two nurses employed by Ndola Catholic Diocese, who make home visits to chronically ill patients three days a week. Each nurse, equipped with basic drugs and medical supplies, and accompanied by a volunteer, makes about 120 patient visits per month. In emergencies, the nurses also arrange for patients to be transported to hospital for more specialist care.

Every Wednesday morning the two nurses, assisted by three or four volunteers, run a clinic at the Centre for chronically ill people who are able to walk. The clinic is visited by about 50 patients, most of whom have symptoms of HIV/AIDS, every week. Medication is provided free of charge. Supplies of condoms are also available. Before the clinic starts, volunteers compile a list of patients expected to attend, based on visits made

Chishilano Centre

The organisational base of home care and TB control in Nkwazi is the Chishilano Support Centre, situated near a grimy charcoal market and open from 9 a.m. to 4 p.m. five days a week. In Bemba, the word *chishilano* means 'legacy' or 'testament', but in Nkwazi it has taken on a special meaning: "For us," says Jacob, a young man living with HIV who regularly visits the Centre, "it means something that you leave behind for your friends".

Built with financial support from foreign donor organisations, the Centre is managed by an elected committee of five local people, and its financial affairs are administered by a Coordinator paid for by the Catholic Diocese.

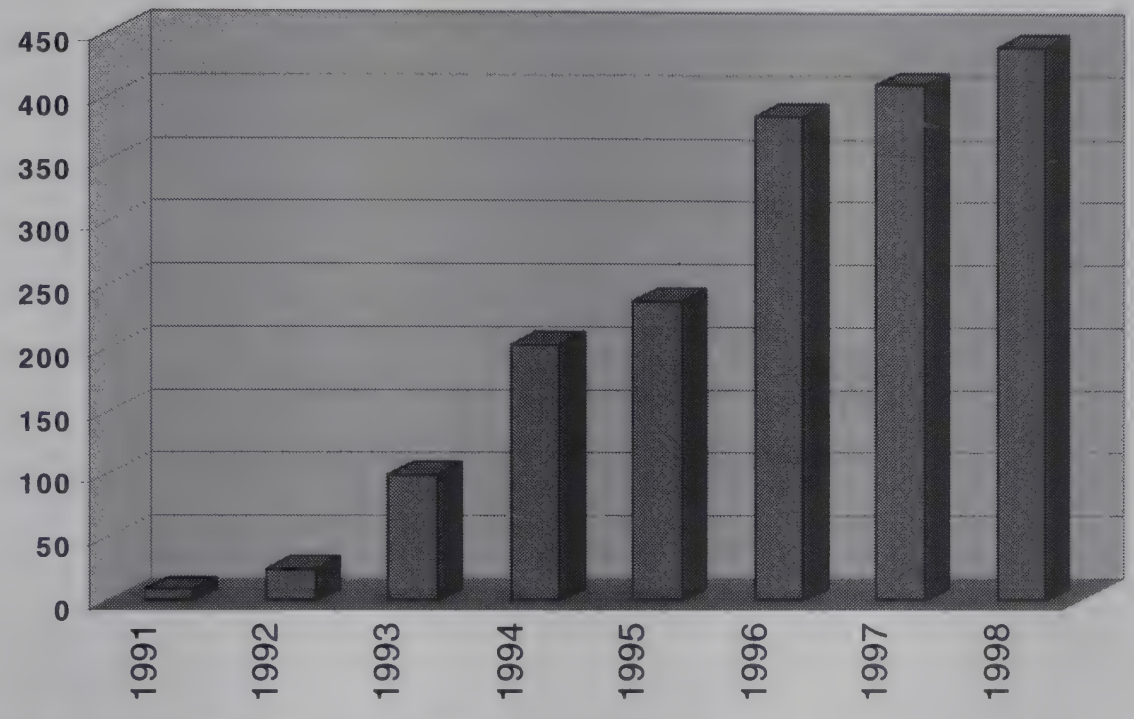
Two local support groups use the Centre as their base. A group of 15 women and three men, all of whom are living with HIV, carry out a range of income-generating activities such as making greeting cards, tailoring and mixing high-protein food. A group of ten young men who are either on TB treatment or have just completed treatment are also based at the Centre. They grow vegetables in the garden outside, and carry out odd jobs such as repairing the approach road to the Centre, constructing a sign outside the entrance, or building office shelves.

The two support groups also organise meetings for health education and spiritual support. "We are happy with Chishilano," said Jacob. "We go to the clinic to collect medicines but then we can't make ourselves go home straight away because we enjoy making friends there."

The Chishilano Centre is also the base for HIV prevention activities in Nkwazi township. Some 20 peer educators, trained and supported by the Copperbelt Health Education Project in Kitwe, carry out door-to-door education and street theatre about STDs, sexual behaviour and HIV/AIDS. In addition, the 'Games for Life' project (supported financially by Ndola Catholic Diocese) organises recreational activities that are healthy, educative and enjoyable for out-of-school children and youth between 8 and 14.

Figure 4: Nkwazi township home care programme, numbers of patients on register, 1991-98

(Average for each quarter to end of June 1998)



Source: Ndola Catholic Diocese, AIDS Department

within their neighbourhoods during the previous couple of days.

The Chishilano Centre is also the meeting point for the 52 volunteer health workers (51 women and one man) who now form the backbone of the home care programme in the township*. On Monday afternoons, the volunteers meet with the two community nurses to decide on the home visits to be carried out in their sections of the township during the week. During the previous two days the volunteers have already done the rounds of chronically ill people in their neighbourhood to determine who is in need of a home visit, and who should come to the clinics on Wednesday morning or afternoon.

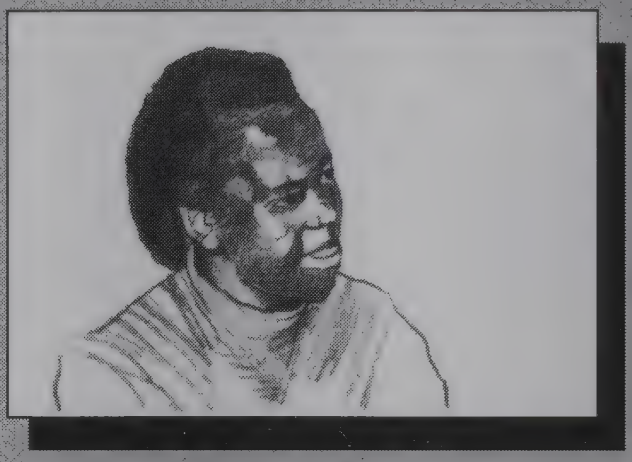
On Tuesday afternoons a volunteer accompanies patients requiring more specialist medical care to the Home-based Care Department at Ndola Central Hospital, where they receive an examination, counselling and medication free of charge. A vehicle from the Catholic Diocese provides transport from the Centre.

The nurses and 14 volunteers who have received additional training also provide counselling to people with HIV/AIDS, or who suspect themselves to be HIV-positive, at the Chishilano Centre, where there is a roster of counsellors on duty every day. In principle, HIV tests are carried out at Ndola Central Hospital, and clients are informed of the results by a nurse-counsellor at the hospital's Home-based Care Department. Between 1996 and 1998, however, a lack of reagents has meant that the hospital has

* Of the 54 volunteers trained between 1991 and 1993, two (both men) have left the programme: one has moved to another town and the other is concentrating on HIV/AIDS education and support work in Nkwazi.

Violet

Violet has been a volunteer health worker in Nkwazi since the home-based care project started in 1991. In 1995 she was one of the first three volunteers in Nkwazi to be trained as an HIV/AIDS counsellor.



She has five children of her own and also looks after three orphans from her husband's relatives. Her husband has a regular job as a gardener for a big transport company. In the past Violet used to work as a market trader, but gave up because her volunteer work was taking up so much time.

"Usually we just do this volunteer work for nothing. Sometimes, like at Christmas, we might get some clothes from the Sisters. Some people in the community, not many, might give us a little money. We try to refuse but they insist and say it's for helping them when they were sick. And just recently we've been able to buy mealie meal from the Sisters at a very low price – that helps a lot.

"I also teach my children about caring for the sick. And whenever I'm not feeling well, my youngest child comes and says 'Mummy, have you taken any medicine? Can I buy you something? Can I do something for you, Mummy?' So I feel that my children are learning from what I'm doing.

"I've never thought of giving up the volunteer work, only of going forward. I feel I've learned a lot. It's one of the most important things in the world that a person can do. And some day I might also be a patient. If ever I fall ill I hope the community will care for me, give me medication, and help me and my family cope with our problems."

been able to carry out only very few HIV tests for clinical purposes.

The AIDS Department of Ndola Catholic Diocese estimates that about one in three households in Nkwazi are looking after one or more orphans, and that the total number of orphans under 18 years of age in the township is about 4,000. The home care programme in Nkwazi does not provide direct assistance to orphans or other children affected by the HIV epidemic. However, volunteers and nurses identify vulnerable children and inform the local branch of Children in Distress (CINDI). In August 1998 CINDI, with financial support from Ndola Catholic Diocese and other sources, was supporting 450 orphans living in families in Nkwazi with food, clothing and school costs.

DOTS in practice

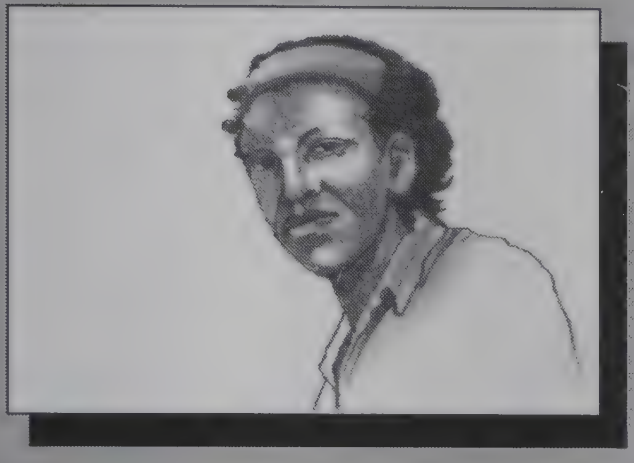
All four walls of one room of the Chishilano Centre are covered with a vividly coloured mural depicting the stages in the DOTS strategy of TB treatment, and the grim consequences of not completing the course.

"A lot of people here can't read," says volunteer Violet Mukosha, "so we thought pictures would encourage them to keep taking their medicines every day."

The programme in Nkwazi is distinctive in that patients are diagnosed and treated

Grace

Grace was one of the first young women to join the income generating group at the Chishilano Centre when it started in 1994. Now aged 27 and a mother of three children, she is still an active member of the group. She is also living proof that TB treatment can be remarkably effective in people living with HIV.



"I was married at the age of 16, but I left my husband after my second child because he was a heavy drinker and was always out late. I was afraid of him, so I came here to stay with my Mum. That was in 1994. Life was hard and I had no other way of making money than by selling sex.

"But when my second child was about four months old I started having chest pains, my legs were hot and swollen, I had a cough, headache, fever and diarrhoea. I had to give up breastfeeding and my Mum started giving my baby light foods. The home care volunteers visited me and I agreed to go on their register of patients. Sister Edith visited me and they took me to hospital, where I was diagnosed as having TB. I came back and went onto TB treatment at home.

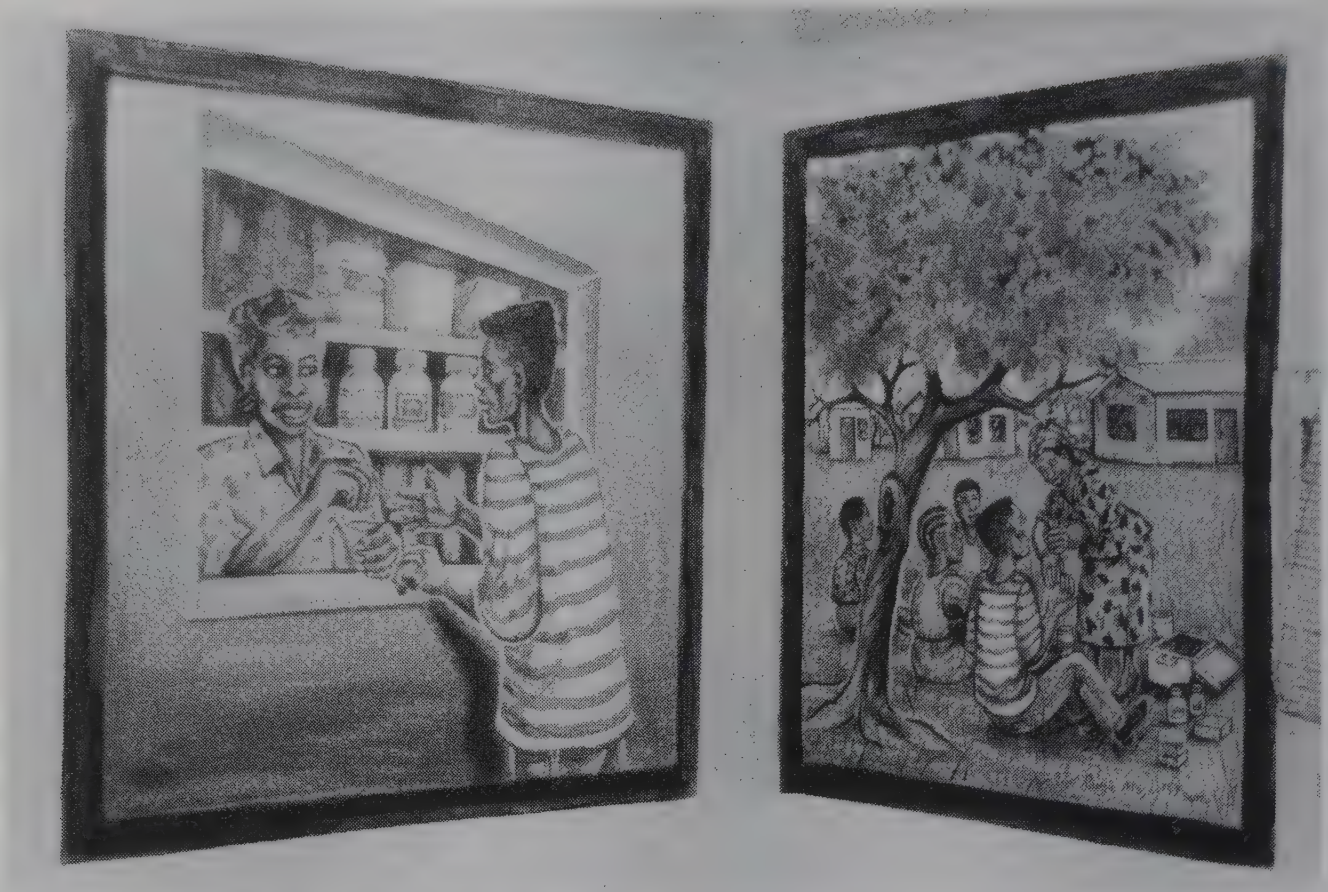
"The nurses from the home care project also counselled me about a blood test for 'the microbe'. They wanted to know how I would react if the result was positive. I assured them I could accept it because I knew my own background very well. When I had the test and was told I had 'the microbe' I wasn't shocked. Sister Edith helped me and other patients with 'the microbe' or with TB to start an income generating project at the Chishilano Centre.

"People told me it was no use me having TB treatment because I was going to die of AIDS anyway. But I finished the course and I made a complete recovery. I even put on weight.

"Now I still go to meetings at the Centre, where we learn about how to look after our own health. I've learned about why you should avoid sex if you have 'the microbe', because you can catch other STDs or be exposed to 'the microbe' again, and it can destroy your body's immune system.

"I do have personal problems, especially when I'm at home on my own, thinking about my future. The home care project has helped me a lot, and I have to keep trying to live a normal life. I've lived with 'the microbe' for more than three years now, and now I'm already into the fourth year."

in the community, without a stay in hospital, although hospital visits are sometimes necessary, for example, when patients require an X-ray. Developed in close collaboration with the District TB Control Officer, the programme began on 1 July 1995. It is implemented mainly by 14 volunteer health workers who were given additional training in TB identification and treatment. The two community nurses from the home care programme provide technical supervision and clinical care, and Ndola Central Hospital provides laboratory and



A mural in the Chishilano Centre depicts the stages in the DOTS strategy of TB control.

medical services whenever necessary.

The programme works in the following way:

Case-finding: Most patients are identified by the community volunteers through routine home visits, or are reported to volunteers by family members or neighbours; some report to the weekly clinic of their own accord; a few are referred to the programme by the local government health centre or Ndola Central Hospital. Initially, the nurse gives every patient who has had a cough for three weeks a course of antibiotics. If there is no improvement, the patient gives three sputum samples for testing at the hospital.

Sputum collection and microscopy test: Volunteers collect sputum from the patient before diagnosis, and after the second, fifth and eighth months of treatment. A volunteer takes samples to the hospital laboratory and brings the results back to the community.

Treatment: The programme follows the National Guidelines for TB treatment*. Drugs are supplied by the Health District or (in exceptional cases only) by the Catholic Diocese, and are provided free of charge to patients. Volunteers visit patients every morning, at least during the first two months of treatment, to observe them taking their medicine and to give them and other family members advice and encouragement.

On Wednesday afternoons the two nurses run a TB clinic at the Chishilano

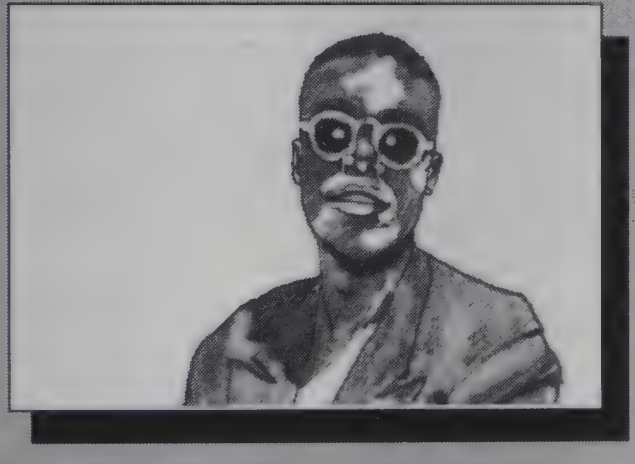
* Smear-positive patients receive the following course: two months of Rifampicin, Isoniazid, Pyrazinamide and Ethambutol, followed by six months of Ethambutol and Isoniazid. Smear-negative patients receive two months of Isoniazid, Pyrazinamide and Ethambutol, followed by six months of Ethambutol and Isoniazid.

Centre. About 15 patients attend this clinic to collect their medicines, to have routine check-ups and to receive treatment for particular problems. They also collect nutrition supplements in the form of mealie meal, HEPS (high energy protein supplement), cooking oil and eggs. The clinic refers patients, whenever necessary, to the TB Unit at Ndola Central Hospital. Patients who are too weak to walk to the Centre receive their supplies of drugs and food through home visits by the nurses and volunteers.

Record-keeping: Patients themselves keep their own individual identification card and also their treatment card, where the volunteer records the medication taken. The community nurses compile the relevant data for the TB District Register

Harold

"I've been a disc jockey ever since I left school," says 29 year-old Harold. "And you know, this kind of job exposes me to a lot of women who start making you their hero, so it becomes very difficult to resist. I've probably had HIV for some years now.



"I started getting fevers in 1994. First I went to a government clinic. Then I contracted an STD and was very sick. A neighbour told my wife about the home care project so I got registered through the volunteer in our section. I was diagnosed as having TB and I really thought I was going to die. I started treatment, and two volunteers visited me regularly. They were so interested in my welfare that I became very open with them. And I actually recovered from TB – it was like a miracle.

"After that I developed herpes zoster and I started asking myself if I could be HIV-positive. Then our fifth child was born. She is two years old now but she has been sick with various ailments. We're spending a lot of our income on medicines and food for her.

"The nurse at the home care project heard about my child's sickness and we had a long talk. After that I came to accept that I could be HIV-positive. Finally I went for a blood test and the result was positive.

"Many people laugh at you if you have AIDS. Only last Saturday, at work, I was telling a man to dress more smartly when he comes to a disco. He knows me quite well and he just said 'You dress smartly but you've swallowed a coathanger*. You're going to die soon.'

"My wife is my strongest supporter. We plan together what we should leave as our legacy to our children. The nurse and the counsellors at the Centre have been very supportive too. But I worry a lot about the future of my children. They are too young to be left as orphans and there's no other member of my family to look after them.

"I had some close friends who were DJs who have died already. But it's too late now and you can't reverse the situation. I'm glad that now I just go for work – I don't go around womanising any more. I have learned to appreciate the company of my wife and children."

* Meaning: "You've become so thin."

The 'community clinic' at the Chishilano Centre: volunteers show patients their records before they see the nurse.

and the Health Department of Ndola Catholic Diocese.

Encouraging results

The TB control programme in Nkwazi has achieved very good results. A total of 126 new TB patients were registered between July 1995 and December 1997*. Nearly all patients had symptoms of HIV infection but fewer than 25% had been tested for HIV. The default rate during this period was a remarkably low 5%, and another 5% transferred out of the programme. One in five patients died before completing treatment: this proportion is typical for countries with high HIV prevalence[18]. However, 69% completed the course and are regarded, for all practical purposes, as being cured of TB.

By comparison, many TB control programmes in low-income African countries which do not use the DOTS strategy have default rates of 25% or more, and treatment success rates of only 15-20%. The fact that, on average, seven out of ten TB patients in Nkwazi successfully completed the full course of treatment is a great encouragement – not just to them and their families, but also to the volunteer health workers. As one volunteer remarked:

"Some days are good. You go out to see a patient and you find him sitting outside his house. He laughs and says: 'I'm happy to see you.' And you tell him: 'I'm happy to see you too, sitting outside like this. Can you walk?' And the patient gets up and shows you: 'Yeah, see, I'm moving around. Let me walk your way a bit.' This is what makes me really happy."

The 69% cure/completion rate in Nkwazi is even more remarkable considering that most of these patients had

* 110 patients (87%) had pulmonary and 16 (13%) extra-pulmonary TB. Of those with pulmonary TB, 60 were smear-positive and 50 were smear-negative.

TB patients receive food supplements to help promote recovery: most patients make considerable weight gains.

symptoms of HIV infection, so their immune systems were already weakened when they began TB treatment. Also noteworthy is the fact that most TB patients in Nkwazi made considerable weight gains, with an average increase of 6.2 kgs over a one-year period.

Mutually reinforcing strategies

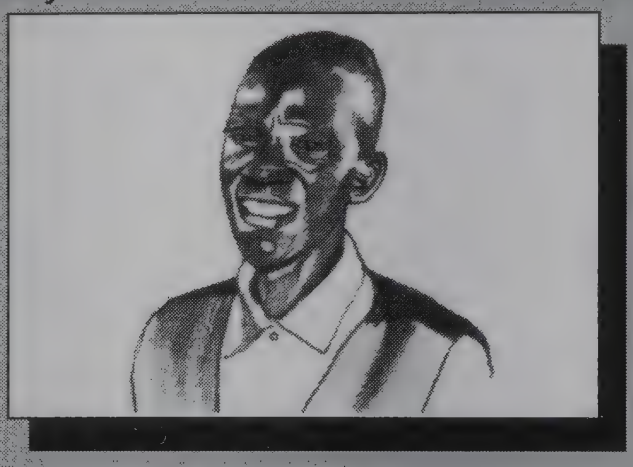
The TB control programme in Nkwazi demonstrates how community-based home care – a strategy developed originally to deal with the impact of the HIV epidemic – can be a highly effective entry point for community-based TB control using the DOTS strategy*. Furthermore, it has positive spin-off effects on the home care programme itself. It demonstrates how TB control can be extremely effective in people with HIV/AIDS, improving the quality of their lives, lifting their morale, increasing their survival time and giving them new hope. It is also extremely encouraging for the family members, volunteers and nurses who are providing them with care and support. In Nkwazi, the TB control programme has also helped to reduce stigma against the Chishilano Centre, by transforming its image from a centre for people with AIDS, to a place where people with any kind of chronic illness can find care and support (see 'Noah' box, page 38).

One of the main elements in the success of the home care and TB control programmes in Nkwazi is the high level of cooperation between the local

* A WHO-sponsored study is being carried out in the neighbouring township of Chipulukusu to evaluate the effectiveness and costs of a community-based DOTS programme.

Noah

Noah and his brother Jack run a small barber shop next to the sawmill in Nkwazi compound. Both have nearly died of TB, and probably owe their lives to the volunteers from the home care programme. But at first Noah completely rejected TB treatment because he did not want people to think he had AIDS:



"I had a cough that I couldn't get rid of. My wife ran away, leaving me with our two young children and my brother Jack. It was Jack who was looking after me at home. But the volunteers took me to hospital, where I was diagnosed as having TB. I was given tablets and told I should report to the Chishilano Centre every week. But I didn't like the idea at all. I didn't want to have anything to do with that place. People called it the 'AIDS Centre', and I didn't want anyone to think I had AIDS.

"So I decided to take my medicine at home, on my own. But after a while I stopped taking it and started drinking a lot again. Soon my TB got worse. The volunteers visited me and found me in a bad state. They took me to the clinic at the Chishilano Centre and I was put on TB treatment again. The volunteers kept visiting me at home. They brought me food, washed my bed linen and even swept the house and the yard. I started going to the TB clinic at the Centre every Wednesday afternoon.

"I finished the TB treatment and I'm now a healthy man. Jack and I have a small barber shop here, and we want to start a second one. I no longer have negative feelings towards the Chishilano Centre. I used to think it was just a place for people with AIDS. Now I realize that it does help those people, but also other sick people. It helps us all to live longer."

community, the Catholic Diocese, the Sacred Hearts Sisters, Ndola Central Hospital and the local Health District's TB Control Programme.

The second crucial element is the involvement of local volunteers, who identify new TB patients, help to run the weekly clinic, accompany patients to hospital when necessary and regularly visit patients to ensure that they complete their course of medication. But what motivates volunteers to devote so many hours of their own time to helping their neighbours? What constraints do they face in carrying out their voluntary work? How can they best be supported so that the programmes which they implement are sustainable in the longer term? The next chapter of this book will address these issues, which are important for any organisation planning to embark on a community-based home care programme.

6. On being a volunteer

When the home care programme in her township was recruiting volunteers, Betty Musowe was one of the first to offer her services:

"One day when I went to church I was given a letter which asked if you were ready to do voluntary work for other people. I thought of my life, of how we all live in a community and how some people suffer. So I volunteered to work for my fellow people who are suffering."

Betty lives with her husband and six children in a small, mud-walled house in a township on the edge of Kitwe. She is one of over 500 volunteer health workers who form the backbone of the home care programme supported by Ndola Catholic Diocese in 23 townships throughout the Copperbelt.

Over 90% of these volunteers are women, mostly in their 30s or 40s. Their educational backgrounds are very mixed. Some have had no formal education or have attended primary school for only a few years; many have completed primary school; and a few have had some years of secondary schooling. Their incomes are generally very low: many experience great difficulty in feeding and clothing their children and paying for them to attend school.

Getting started

Like Betty, most volunteers have joined the home care programme in response to an appeal through their local church. Others have offered their services after seeing how home care volunteers have assisted their own family members, neighbours or friends in the past, and a few have been asked personally by a community or religious leader to become volunteers. Some of those who initially expressed an interest in becoming volunteers, however, withdrew before being trained, after learning that they could not expect to receive any payment for their work.

Volunteers receive two weeks initial training in basic hygiene, HIV/AIDS and other sexually transmitted diseases, home nursing, nutrition and first aid. The training manuals used are Bemba language editions of *Facts and Feelings about AIDS* and *AIDS in your Community*[19]. On completing the training course, each volunteer receives a Bemba edition of the *AIDS Home Care Handbook* published by WHO in 1993, and a bag containing a towel, soap, disinfectant, scissors, two small basins, rubber gloves, gauze, strapping and oral rehydration salts. Some volunteers are later trained as 'DOTS supervisers' for TB care within the community.

Before they can become fully involved in home care, however, many volunteers have to fight a personal battle. Judith, for example, had to overcome opposition from her husband:

"At first my husband was not in favour of it. He used to say: 'What do you bring back from home care? You don't get paid for it. If you bring TB or AIDS in here you'll be in trouble.'"

Other volunteers have to grapple with their own fears, and even feelings of shock or revulsion, when they first come into contact with chronically ill patients. Eileen remembers how she overcame these feelings:

"You go back home and you start thinking, 'If I don't go back, that patient will think bad things about me. I will go back. I'll persevere...' So you go back again to that house, and you keep going back, and your attitude changes. You become stronger."

Changing demands

When the programme began in the early 1990s, the basic role of the volunteer was to support family care-givers in providing

care and support within the home to people who are chronically ill, mostly with HIV/AIDS or TB, or both. Volunteers had a set of clearly defined, basic responsibilities:

- identifying people in their neighbourhoods who are chronically ill, and arranging for them to be seen by a nurse from the programme
- visiting patients at least once a week to check on their condition and ensure that they are taking their medication in the prescribed doses and at the correct times
- showing family members how to give basic nursing care, or if necessary providing such care directly
- arranging for patients and families to receive welfare support from the programme: for example, free or subsidised food, blankets, clothing, transport to hospital, and assistance with funerals
- providing emotional and spiritual support to patients and their families
- carrying out practical jobs such as cooking food, sweeping the house and yard, washing clothes and bed sheets, or fetching water and firewood.

These responsibilities were soon increased by adding TB control using the DOTS strategy, in which volunteers identify new TB patients in their neighbourhoods, and also visit patients to ensure they take their medication every day.

As the HIV epidemic has progressed, the volunteers have taken on additional responsibilities. Many have become

Volunteers visit patients at least once a week: their workload has increased greatly since the Copperbelt home care programme began in the early 1990s.

involved in providing care and support to orphaned children, in assisting aged grandparents who are caring for orphans, and in helping widows cope with the practical problems of bringing up children with no regular income. Some have also been trained as 'support counsellors', and may spend several hours a week counselling people before and after an HIV test, or giving pastoral support to people living with HIV/AIDS.

Some volunteers have become specialised in specific, time-consuming tasks, for example, helping to organise the weekly home care clinic at the local hospital. Others help home care nurses to run the local community clinic and to administer the TB control programme, for example, by keeping records and dispensing medication and food supplements.

The numbers of patients on the home care registers of the townships have increased enormously since the start of the programme. In the early 1990s, whenever a new home care project began in a township, there were only one or two chronically ill patients for each trained volunteer. By 1998, however, the numbers had increased to an average of ten patients per volunteer, adding greatly to the volunteers' workload.

The numbers of chronically ill people who have no family support at all have also increased enormously. These patients require much more practical help and nursing care, as well as emotional and pastoral support, than those who are cared for by members of their own family. At times volunteers are called upon to support their patients right up until the moment when they die. When long-term home care patient Boniface felt he was nearing the end of his life he sent for Judith Chanda, the volunteer who had been visiting him for many months. She responded immediately:

"I went there and sat down by his bedside. Whenever I tried to move, he held me and pleaded that I should stay near him. Then he started talking and said a few words that I wrote down in my notebook. He thanked the home care group and asked us to look after his children. Now imagine how I felt, being the one who was with him until his death, who held him while he was dying. He died in my hands – this is still in my mind."

Perseverance

Some volunteers have remarked that the most important human quality required for voluntary home care work is perseverance. It is easy to understand why. The work the volunteers do is physically and emotionally exhausting. They walk long distances, in all weathers, and may be called out to visit a patient at any time of the day or night. Some of the work – such as washing soiled bed sheets and clothes, or bathing patients with open sores – can be unpleasant and even distressing. It is also very time-consuming: most volunteers spend at least one full day a week carrying out their many home care tasks for very little – if anything – in the way of material rewards.

The heavy demands on volunteers' time sometimes lead to a clash of responsibilities towards patients on the one hand, and family members on the other. Eileen explained:

"The work is hard. You might be thinking of doing something at home, and then someone will come looking for you and asks you to go and see a patient. Then you end up leaving your baby with your grandfather, who complains that it isn't his responsibility. And the truth is that five minutes is not enough time to talk with a patient. You need an hour or more. This is the problem we face."

The programme provides most patients and their families with food and other basic necessities, but the supplies available are never enough to meet the needs. Volunteers sometimes feel a sense of frustration – and even of personal failure – when they are

Jacqueline

"The other volunteers supported me a lot when I was nursing my only daughter," says Jacqueline, an unmarried 45 year-old lady who looks after five orphaned children in Ipusukilo. "She passed away, leaving me with two grandsons aged four and nine. I had been trained as a health volunteer, so I knew my daughter was suffering from AIDS and the younger boy could also be HIV-positive.

"I wanted to be trained as a volunteer because I was interested in getting more knowledge about health issues. We learned about how to take care of the sick and also to protect ourselves. The community recognises us and respects us.

"But sometimes I do think about giving up, like during the rainy season, when my roof is leaking. And sometimes the work is very unpleasant. Once I went to a house, and as I opened the door there was an overpowering smell like a decaying corpse. There on a mat in front of me was this poor bundle of humanity, like a lamb waiting to be slaughtered. I opened the window and saw that the man's body was covered in sores and maggots. And the pain in his eyes... There I was, alone with this burden. I thought 'Doctor, where are you? Sister, where are you? This is unbearable. O God, how can I go on? Isn't there someone out there who cares about me, a volunteer with limited knowledge, left to do this work?'

"What keeps me going is my religious faith, and the support of the nurses and my fellow volunteers. And I do appreciate the support I get from the project for the orphans I look after. I like the meetings we have with volunteers from other places, where we exchange gifts. But the volunteers need some kind of project to earn some money together.

"Sometimes the situation seems hopeless, because the number of people with AIDS keeps increasing. But people here are becoming more concerned about AIDS and more helpful to one another. Those who were afraid of people with AIDS are being educated and are gradually accepting them.

"Sometimes I wish there was some kind of reward for what we do. But I can't stop now. I'm too deeply involved. My finger is woven into the basket."

unable to help patients as much as they would like: "You treat their wounds and sores. And then you just leave them like that. It pains me a lot," said Loveness.

Many volunteers carry on assisting their patients even though they have barely enough income and food to support their own families. Sometimes this affects their work, as Beatrice observed:

"There are some patients who cannot move or change position on their own. Now how can someone on an empty stomach lift a patient? You might drop them and the patient might say 'These people have finished me now', whereas what really happened is that you were feeling dizzy with hunger. Sometimes we even long for the patient's porridge."

Volunteers also have to cope with a lack of practical and moral support from their

own communities, even from their churches. This is surprising, given that most volunteers were recruited through their churches. Judith Mumbi, the community nurse who was a co-founder of the home care programme in Ipusukilo township, explains:

"We expected the churches to give encouragement to the volunteers, to pray with them, even to support them financially. They haven't done that. But I think we are partly to blame because the volunteers have not been reporting to their churches about their work. They've been reporting to us, in the programme. So most of the time the church leaders don't know what the volunteers have been doing. But we're working on that now, so that the volunteers also report on their work to their churches."

On some occasions volunteers also have to cope with patients or community members who do not understand the voluntary nature of their work and accuse them of gaining financial or other material rewards from the home care programme:

"People tease us," said Janet. "One day, when Mrs Mulenga and myself were on the way to visit a patient, people greeted us and said 'Ah, you have truly put on weight thanks to the soya beans and milk you are getting from home care'. I told them we get nothing, that even the medicines go to patients, not us. Just because we are joyful when we visit patients, people think we get paid."

Maintaining morale

Given the demands which their home care activities make on their time, energies and emotions, it is hardly surprising that some volunteers decide to give up the work. However, about seven in every ten volunteers trained between 1991 and 1994 were still active in 1998. What motivates so many volunteers to maintain their involvement in the programme, despite their own poverty and the numerous problems they encounter in the course of their work?

For many volunteers, religious conviction is an important driving force behind their commitment to home care. Most were recruited through the churches, and their Christian faith continues to motivate them, despite the numerous constraints and problems they encounter. Others are motivated simply by feelings of neighbourly love. Sometimes these feelings seem to assume the status of a personal mission in life. Henry, for example:

"For me, this is my vocation since childhood. If for two days I don't visit patients, I do not feel comfortable. My heart pains. Visiting them is like a medicine to cool my heart."

Volunteers feel encouraged when they see the health of their patients improve, as Helen testified:

"I feel happy when I see that a patient who has been critically ill can now walk around. Then I think of God working through me. I say to myself that without my work, this person could have died by now. So God's power and mine have enabled this person to survive. This brings a lot of happiness to me, and also to the community."

Feelings of group solidarity and a sense of pride in what they have achieved together help to inspire many volunteers. Bornwell describes how the volunteers in his township feel:

"We meet every Thursday. The Sister gives a short class, but then we ourselves – the ones directly concerned – we handle the discussions about our work and our problems. Through these meetings we feel like we belong to an extended family which can assist us when there is a need. Another thing which makes me happy is the knowledge which I get from my friends, free of charge."

Some groups of volunteers also organise social events which help to maintain group morale. At so-called 'secret friends' meetings, for example, volunteers from

Home care volunteers meet regularly to exchange information, plan activities and improve their own knowledge and skills.

two different townships come together and exchange gifts with one another. These meetings are not only enjoyable in themselves but also enable the volunteers to have a fruitful exchange of ideas, information and experiences. Sometimes they also lead to feelings of friendly rivalry, which can help to motivate volunteers and programme staff to be more imaginative and innovative in their work.

A supportive programme

Support from the programme management is important not only in helping to maintain high morale among volunteers, but also in helping to make their work effective. This support takes several forms:

Appreciation: Programme staff try to demonstrate that they value each and every volunteer as individuals, and appreciate their contributions to the programme. Says community nurse Judith Mumbi:

"Each volunteer has to be appreciated for the work they do. You can do that in many ways, for example, by listening to them when they come with their problems, and showing them respect."

The annual Christmas party, when the volunteers receive gifts for themselves and their families, is another way in which the programme staff show their appreciation of the volunteers' dedicated work.

Supervision and ongoing training: The volunteers are not left to fend for themselves after their initial training course. Once every week or fortnight, they meet with the community nurses to discuss their work and problems, and to reinforce

or improve their knowledge and skills. Volunteers appreciate this kind of supportive supervision and are keen to take advantage of any opportunity to improve their capacities.

Technical and logistic support: Home care volunteers do not work in isolation, but function as an essential link between their own communities and the home care and TB control programme. The technical and logistic support provided by the programme – in the form of community nurses, drugs, food, transport, and referrals to hospital for free outpatient treatment – is vital. Without this support, the volunteers would be unable to help their patients gain access to the health care and social support that can make such a difference to the quality of their lives.

Incentives: All the volunteers joined the programme in the knowledge that they would not be paid for their work. Throughout the 1990s, however, economic conditions in Zambia have continued to worsen, making it more difficult for people on low incomes – as is the case for most volunteers – to survive. At the same time, the volunteers' home care workloads have increased, leaving them even less time for income-earning activities and family duties. Many volunteers also have to cope with the added burden of caring for chronically ill family members, and of looking after young orphans after the premature death of a relative.

These developments have prompted many volunteers to ask whether the 'big office' (i.e. the AIDS Department at Ndola Catholic Diocese) in Ndola could help them economically. The programme management has responded by making two types of 'incentives' available to volunteers. First, volunteers can purchase a 25 kg bag of mealie meal, at 50% of the market price, for the needs of their own families each month. Second, in six townships the AIDS Department has made a loan or a grant to a group of volunteers for income-generating activities, such as poultry farming and producing sunflower oil. It is likely that the programme will have to provide many more volunteers with the opportunity to participate in joint income-earning projects of this kind in the future.

A listening ear: The AIDS Department of Ndola Catholic Diocese tries to stay well informed about the changing problems and needs of the volunteers, and to respond to these in a sensitive way. In 1997 the Department commissioned a research study on the motives of the volunteers for working in home care, and the problems and constraints they encounter*.

The study identified some issues which could threaten the effectiveness of the programme and the continued participation of a number of volunteers. In a few communities, for example, there was a lack of communication between local volunteers and the nurses in charge of programme management. Some volunteers also complained that nurses failed to consult with them when planning for future activities in their community. For the most part, volunteers tended to avoid open disagreement with the nurses, preferring to bottle up their grievances rather than bringing them into the open. This led to unhealthy tensions which needed to be resolved. The AIDS Department has responded by organising two workshops for staff and volunteers, and by giving volunteers a voice in the

* The study was carried out in 1997/98 by Petri Blinkhoff and Edith Lungu, assisted by Esther Mambwe and Esaya Bukanga. The researchers interviewed 31 volunteers (24 women and 7 men) in focus group discussions in four townships; eight volunteers were also interviewed individually and accompanied on home visits. In addition, the researchers interviewed a small sample of people living with HIV/AIDS, family care-givers and nurses from the programme.

selection of their community nurse.

Of potentially even greater consequence for the programme are the differences in programme policies and activities from one township to the next. Sometimes this has led to groups of volunteers feeling that they are at a disadvantage compared with the 'lucky' ones in other places. Some townships, for example, have the use of a four-wheel drive vehicle from the programme to take patients to hospital, to transport food and medicines, and to take volunteers to meetings outside the township. Other groups of volunteers, however, have to share a vehicle with those in another township, or have no vehicle at all available for their use. Another contentious issue is the availability of material support for patients. Some home care projects, for example, receive donations of clothes from local or foreign well-wishers and give these to needy patients, while the project in the neighbouring township has no clothes at all to give away. As one home care volunteer said, with feeling:

"I have heard from my friends that if a patient in that township cries for clothes he gets them. But in our programme there is nothing like that, only mealie meal. This is discouraging – others get clothes to give to their patients but we don't. It would be better to do it for all of us."

The question of access to loans for joint

Transport may pose problems for home care programmes: some townships may have to share vehicles with others, or make do without a vehicle.

income-generating schemes is another case in point. In 1997/98 a few groups of volunteers received loans from the AIDS Department to help them start small-scale income-generating schemes. This is a bone of contention with volunteers in other townships, who have not yet received such support.

These differences arise from the large degree of autonomy which each home care project has. In principle, local autonomy is to be welcomed because it stimulates local initiative and ownership. However, if volunteers are not sufficiently informed about – or involved in – decisions affecting their work, they can feel alienated and demotivated. The AIDS Department is aware of this danger and is considering how to establish clearer overall policy guidelines, while preserving the maximum degree of local autonomy in each township home care project.

The volunteers who took part in the research study were pleased to be asked for their opinions about the programme and the problems which they face. As one woman said: "It feels as if we have been relieved of a burden." Another added: "Please go and speak on our behalf to those who are above you. Tell them about our needs, to remember us please, so that we can feel encouraged and work well."

Personal development

The research study also asked the volunteers what had changed in their lives since they joined the home care programme. Without exception, they stated that becoming a volunteer had brought about positive changes in terms of their own personal development and self-esteeem, in particular:

Attitudes: Many volunteers feel that the programme has helped them to gain self-confidence when dealing with other people. Ruby, for example:

"I am gaining maturity every day. I wasn't able to speak in public before. But now, after experiencing a lot of things, I am able to teach others how we can live a better life, and how we can safeguard ourselves from diseases."

Some feel that they now have a more compassionate attitude towards the sick, and in particular towards people with HIV. David said:

"I don't want people to point a finger at a patient, or to say 'This person will die of AIDS'. I get annoyed if people do that."

HIV/AIDS awareness: Through their involvement in home care, many volunteers have become more aware of sexual and reproductive health issues, and of how HIV is transmitted. This has led some to change their own sexual behaviour, as one woman volunteer admitted:

"In the past I used to sleep around a lot, but after hearing that you end up getting this disease I have stopped."

Another volunteer explained that she has done away with the traditional practice of inserting herbs into the vagina because of the heightened risk of HIV transmission through 'dry sex'.

Capacity building: Many volunteers feel that they have gained a great deal of satisfaction and self-confidence from increasing their knowledge of modern medicine, which they can use within their own families. Joy, for example:

"Before this programme I was ignorant. When taking my child to hospital I used to fear the nurses and wasn't able to explain properly what was wrong with my sick child. But now I have experience, and I can answer with confidence whatever question a doctor or nurse might ask. And I now know how to give medicines to my children. For example, Septrim – sometimes I used to give my child four spoons in one go so she would recover quickly! But now I know that if I do that I am harming my child."

Volunteers who have had little or no schooling have appreciated the home care

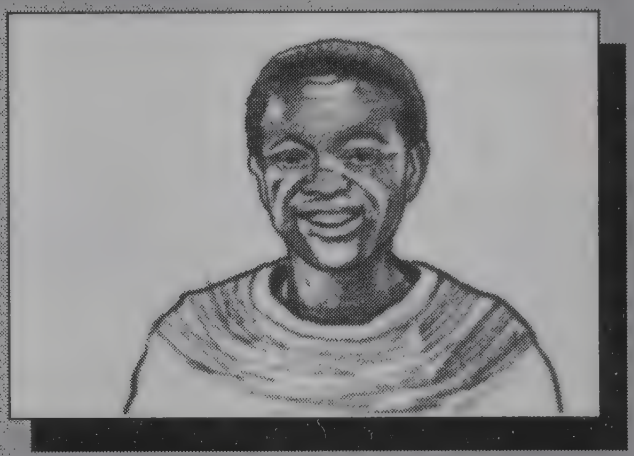
programme because it has helped them to compensate for their lack of formal education. Charity remarked:

"Being the first-born in our family, I didn't go to school. Whenever there was sickness in my home I used to go to the witch-finders. Now, through this programme, I have changed. I am awake now."

Community recognition: Through their home care work, many volunteers have gained a great deal of respect from their patients and other members of the

Rosemary

One of only two volunteer health workers in her section of the compound, Rosemary Ngulube has six children and her husband works as an electrician. She was one of the first group of volunteers in Ipusukilo trained in 1993.



"What helps to motivate me is the recognition I get in the community as a care-giver. I also find joy in caring for the sick. Besides, I never went to school. Before joining the home care programme I didn't know how to read and write, or to speak English. But now I can do these things, and I also have two certificates of my own from training courses I attended.

"At the hospital I used to be scared to ask for any information. But now, with my identification badge, I'm regarded as one of the staff. Nobody ever asks me where I'm taking a wheelchair to or why I'm in the lab.

"I have the full support of my husband and all the members of my family. My children are quite proud of me. Being a volunteer has also helped me to take care of my own family. My brother fell ill with TB and I nursed him, but unfortunately he died. Then my first-born daughter lost a child, and her husband died, and she developed a lot of complaints – cough, loss of strength, night sweats, loss of appetite.

"When I asked her why she was losing weight she said she was depressed from losing her child and her husband. People were saying that she had not kept to the rules of mourning an unripe child, so the ghost of the baby turned on the parents. But because I was familiar with the signs of HIV/AIDS, I started wondering if my daughter could be HIV-positive.

"I started counselling my daughter and she agreed to get her blood tested for HIV and her sputum for TB. She started treatment and went back to Lusaka, but soon she was admitted to hospital so I rushed down there to care for her. She had so many gadgets all over her body. I've never seen so many things on a sick person. Even the electrical company doesn't have as many wires on a single pole.

"I cared for my daughter there until she died. I was strong and followed all the instructions from the nurses on the ward. One of them even asked if I was a retired nurse! Who – me a nurse? But who knows, maybe one day in the future..."

community. Neighbours ask for advice about health problems and other issues. "Whenever there are problems they ask for me. The whole community knows me and I am greeted wherever I go," said David.

Many volunteers have become informal leaders within their own local communities. Even though this places heavy demands on their time and can be emotionally draining, they appreciate the increased social status that comes from their work, as Kangwe remarked:

"What helps to motivate me is the recognition I get in the community. It's like the sacred status of a traditional healer."

Gender matters

It is a cruel twist of irony that over 90% of home care volunteers are women, most of whom are already directly affected by the dual epidemic of HIV/AIDS and TB, for example, by caring for chronically ill family members or relatives, or by taking orphans into their own families. Women volunteers are, in effect, carrying a double burden of increased care: in their own families and also in the wider community.

It is important to understand the practical and cultural reasons for the predominance of women volunteers. Most volunteers are recruited through the churches, where women tend to be more regular than men in attending services of worship, and so can be contacted more easily. Women are also likely to spend more time within the community than men, many of whom are often away working or seeking employment. Deeply rooted cultural factors are also involved. Women are traditionally the main care-givers within the family and the wider community. Society expects women to be the providers of care, and indeed women expect this of themselves. As a trainer of home care volunteers remarked:

"A woman has been trained from childhood to be a care-giver. And she's conditioned to such an extent that she neglects her own care for the sake of the others."

Men, by contrast, are not expected to be care-givers. Their contributions to community-building tend to be more individualistic and are generally made on a 'one-off' basis rather than as a regular commitment. Men are more likely to help with, for example, constructing a building for a community clinic than in helping to organise the clinic on a day-to-day basis.

The few men who have become home care volunteers in the Copperbelt programme sometimes have to cope with the taunts and jibes of other men, who dismiss their home care activities as 'women's work'. Yet the male volunteers have generally proven themselves to be just as competent as the women, and the advantages of increasing their numbers could be considerable. Apart from lightening the burden on women volunteers, the involvement of more male volunteers could help the programme to reach more men. Many men would be more willing to discuss sensitive issues, such as sexually transmitted infections, with male than with women volunteers.

It is by no means certain, however, that women volunteers would be willing to work alongside men in home care. Many women volunteers seem to gain inner strength and self-esteem from the company and support of other women. There are also serious practical difficulties in organising meetings where women and men sit together and are expected to participate equally in discussions. Traditionally, Zambian women defer to men and often feel inhibited about expressing their own opinions when men are present. As one woman community activist observed:

"You find you start holding yourself back to give your husband a chance to talk. This happens even with women who know their own minds and are very vocal in groups of women. But because of tradition they are supposed to keep silent and let

their husband speak the wisdom."

These traditional attitudes are not set in stone, but are evolving in response to changes in the social and cultural environment of the day. The Ndola Catholic Diocese, through its Development Education Programme, is training groups of women and men to re-appraise their relationships and attitudes towards one another. At the same time, some men are starting to come forward with their own ideas for becoming involved in home care. In a township on the outskirts of Ndola, for example, a group of ten young men – all of whom have been treated successfully for TB – have asked the AIDS Department of the Catholic Diocese for training as volunteers in home care for people with TB. The Department will consider this request, however, only if it is endorsed by the local home care volunteers, all but one of whom are women.

Wider issues

Despite the numerous constraints and problems which they face, the volunteers in the Copperbelt home care programme have shown enormous creativity, resilience and commitment. The programme has generated considerable momentum at community level. Although some volunteers have had to give up their home care work because of the heavy demands it makes on their time and energies, new people have always come forward to take their places. Moreover, the number of townships requesting training for their own home care volunteers continues to increase.

The programme has demonstrated how volunteers can play a highly effective role in helping to close the 'home care gap', in promoting effective TB control at community level, and in reducing the stigma associated with HIV/AIDS and TB. But can this 'model' of community-based home care be replicated in other places that are affected by the dual epidemic of HIV/AIDS and TB? And how sustainable is this kind of programme in the longer term? These are the issues that we shall address in the final chapter of this book.

7. Managing a crisis

The dual epidemic of HIV/AIDS and TB has already caused enormous grief, pain and suffering to millions of people throughout the world. And in Africa, Asia, Latin America and the Caribbean, the worst is still to come. The countries of sub-Saharan Africa will bear a particularly heavy burden of chronic illness and premature death.

In Zambia, for example, in the decade between the year 2000 and 2010, an average of more than 300 people per day will develop AIDS, and the number of new TB cases will rise to 150 a day[20]. The cumulative total of AIDS deaths in Zambia is set to rise from 400,000 in 1998 to 1.2 million by the year 2005, and to 1.8 million by the year 2010[21].

Health systems in most of sub-Saharan Africa lack the financial, technical and human resources to provide adequate care and support to the millions of people who are already chronically ill with HIV/AIDS and TB, let alone meet the needs of those who will fall ill during the next decade. These needs are not only for medical and nursing care, but also for economic, psychological, social and spiritual support. The only strategy which has demonstrated its potential to meet these needs on a wide scale is community-based home care, combined with the DOTS approach to TB control.

This book has described how the home care programme coordinated by Ndola Catholic Diocese in Zambia's Copperbelt is helping to improve the quality of life of thousands of people who are chronically ill with HIV/AIDS, and to reduce the stigma associated with the epidemic. This programme, which prioritises people in low-income townships, appears to have achieved high coverage of its target population, at reasonable cost. It demonstrates that, at least in urban areas, it is possible to greatly reduce the 'home care gap', even in very poor communities.

The programme also demonstrates how community-based home care and the DOTS strategy of TB control can be successfully integrated, each enhancing and reinforcing the impact of the other. Home care strengthens TB control through the involvement of community volunteers in identifying new TB patients, and in ensuring that patients take their TB medication every day and attend clinics regularly for check-ups.

Effective TB treatment, for its part, gives a massive boost to home care for people with HIV/AIDS. It lifts the morale and improves the quality of life of people living with HIV/AIDS, increases their survival time and enables parents to spend additional months or even years with their children. It also gives enormous encouragement to family care-givers, community volunteers and health professionals, who otherwise can become discouraged and depressed after caring for people with HIV/AIDS whose health continues to deteriorate.

The day-to-day activities of the Copperbelt programme are implemented largely by local volunteers, with technical support and supervision from nurses working within the community, co-ordinated by a small central office and backed-up by government health services. This community-based approach is the key to the programme's high coverage of its target population and its relatively modest cost.

Mobilising volunteers

There is now an urgent need to implement community-based home care for people with HIV/AIDS and TB more widely, not only in Zambia but also in many other parts of sub-Saharan Africa. This does not mean trying to replicate every detail of the Copperbelt programme in other contexts,

but applying the main strategies of the programme to different situations, making whatever modifications are needed for local conditions.

Crucial to the success of the Copperbelt programme is the mobilisation of over 500 volunteers working within their own neighbourhoods. Although this is an impressive achievement, the number of volunteers involved is still small compared with the needs on a national scale. To achieve national coverage in Zambia, home care programmes would have to mobilise well over 10,000 volunteers. Many would have to be located in rural areas, where about 40% of the population lives, and the cost of training and supporting them would inevitably be greater than in towns and cities.

There are no precedents in Africa for the successful mobilisation of health volunteers on a national scale, over a sustained period of time. Indeed, the experience of promoting the role of voluntary community health workers (CHWs) in national primary health care programmes in a number of African countries during the 1980s was generally disappointing.

The disappointments of the past, however, should not be allowed to cloud the prospects for the future. The CHWs of the 1980s were expected to carry out a wide range of tasks, mainly in the field of disease prevention, with little or no technical back-up or other support from the formal health system. The volunteers in the Copperbelt home care programme are

Volunteers can help to reduce the 'home care gap', even in very poor communities.

in a different situation. They have a smaller range of clearly defined responsibilities, and are backed-up by a programme which provides patients with a basic level of medical and nursing care, as well as social and economic support.

Volunteers, however, also need a certain amount of economic and social security to be able to function. The Copperbelt home care programme has found it necessary to offer volunteers some modest material incentives, such as food at heavily subsidised prices, and – in a few cases only so far – loans or grants for joint income-generating projects. To compensate for the ever-increasing demands on their time, the programme may well have to offer many more volunteers the chance to participate in income-generating projects in the future. The programme will not have the resources, however, to provide volunteers with salaries or other regular, direct payments in cash or kind.

Given the poverty of most communities in sub-Saharan Africa, is it realistic to expect large numbers of people to volunteer to work for the benefit of others, in return for few, if any, material rewards? The experience of the Copperbelt home care programme suggests that many people on low incomes – at least in urban areas – are not only willing to become home care volunteers, but that they benefit greatly from the knowledge, skills, self-confidence and increased social status which they acquire through their voluntary work. Their initial motivation, however, is not their own personal development, or the prospect of material rewards, but a deeply felt sense of compassion for – and solidarity with – other members of the community.

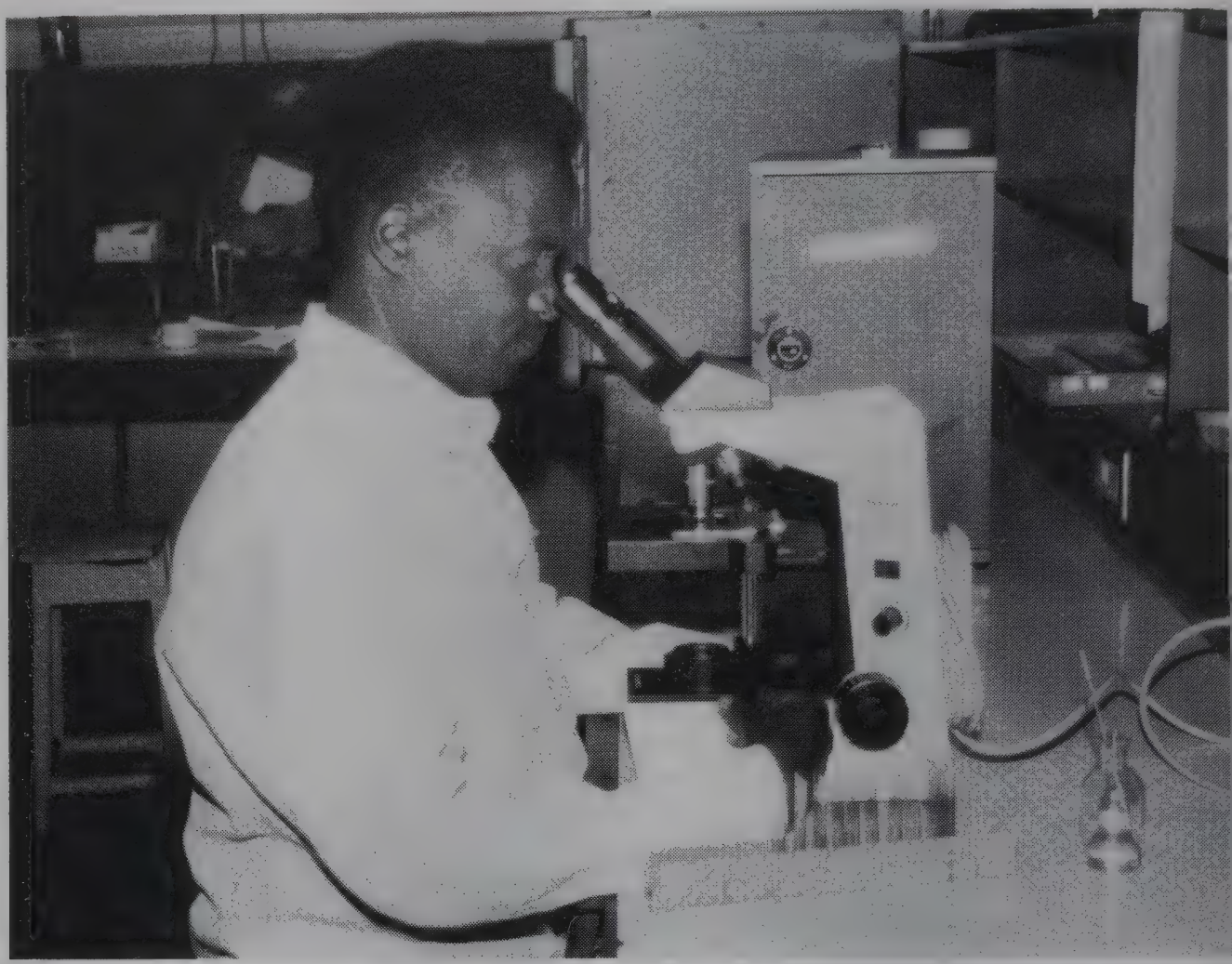
It is no coincidence that most volunteers in the Copperbelt programme were recruited through their churches and continue to be motivated by their Christian faith. The churches and other faith communities, however, are only one pathway for mobilising volunteers for home care programmes. Well-motivated people with some experience of social service can also be found in women's organisations, youth movements and neighbourhood associations of various kinds. People active in these organisations also need to be offered the chance to become home care volunteers. It is important, however, that people themselves be given the opportunity to offer their services, rather than being appointed by a programme manager who may not be well placed to decide who is most likely to be acceptable to the local people.

Sustaining home care

Home care programmes cannot be sustained by volunteers on their own, but need the support and active involvement of many different sections and levels of civil society and government:

Communities: The main front-line providers of home care are family members, especially women and girls. Home care programmes are intended to support family members who are giving care and support to people who are chronically ill, and also to provide direct assistance to those whose families are unable to support them. However, the sustainability of the programme is greatly enhanced when families themselves make a contribution in cash or kind to the programme. In the Copperbelt programme, for example, members of some communities have contributed their labour to construct a building for the community clinic. In addition, most families receiving food from the programme pay a proportion (usually 10%) of the retail price, and the income raised is ploughed back into activities such as buying more food and paying for funeral expenses.

Government health services: TB control is primarily a government responsibility, requiring a reliable supply of drugs, an efficient system for laboratory testing of sputum samples, X-ray services,



Tuberculosis control requires an efficient system for laboratory examination of sputum samples.

and clinical staff who are able to monitor patients' progress and adjust the treatment if necessary.

Governments are not directly responsible for home care programmes at community level. It is in their interest, however, to support home care, which can help to relieve the pressure on heavily congested hospital wards and outpatient departments. Support from government health services can take the form of, for example, training home care volunteers, assigning nurses to work in home care programmes, and offering free or low-cost treatment and laboratory services (including HIV testing) to patients with chronic illnesses who are referred by a home care programme. In general it is neither feasible, nor desirable, for volunteers to receive salaries or other regular payments from government. Not only is this unsustainable in the longer term, but it tends to stifle local initiative and results in the volunteer becoming, in effect, a health worker rather than a representative of the local community.

The non-governmental sector: The greatest potential for expanding community-based home care and TB control rests with non-governmental organisations. Religious institutions and large NGOs can take responsibility for the management of integrated home care programmes, in which care and support for people with HIV/AIDS and TB control are

promoted along with HIV prevention. This is the approach taken by Ndola Catholic Diocese through its AIDS Department. It can be adopted by any large religious institution with responsibility for a particular geographical area, such as a Province, or by an NGO working in health and development. However, organisations considering becoming involved in home care and TB control need to ensure that they have the technical expertise, the logistic and administrative infrastructure, and the necessary funding to carry out this work effectively.

Church and mission hospitals have been in the forefront of home care for people with HIV/AIDS in Zambia and many other African countries. Most have already made the move from providing home care directly through mobile teams of health workers, to supporting the work of volunteers within their own communities. Their commitment and creativity are now needed in facing the challenge of expanding the coverage of community-based home care and TB control, especially in rural areas.

The law and police: There is much that the legal system and the police can do to support home care in the widest sense, for example, by combatting domestic violence and by protecting widows from property-grabbing by relatives. In addition, a simple

The police can help to promote home care by protecting widows from property-grabbing by relatives.

change in the legal requirements for certifying death would ease the financial burden on many low-income families. At present, the law in Zambia requires that the police have to issue a death certificate, which is generally issued only in a hospital. Since the cost of transporting a dead body to hospital is three or four times more than for a living person, many families send a dying relative to hospital rather than keeping the person at home. This is not only an unnecessary expense but can also cause great emotional stress.

The business sector: Local businesses can make an important contribution to the long-term sustainability of home care programmes through regular contributions in cash or kind. They can, for example, sell basic foods at heavily subsidised prices to home care programmes; provide groups of volunteers with supplies such as rubber gloves, boots and raincoats; or provide transport in the form of motorbikes or bicycles.

The mass media: Radio, television, newspapers and magazines can help to promote public participation in home care and TB control by highlighting how successful home care and TB control programmes are making a real difference to the quality of people's lives. Success stories need to be documented and disseminated more widely in order to encourage more volunteers to come forward and to promote greater community understanding of home care and TB control.

The international aid community: Home care programmes in Zambia and most other parts of sub-Saharan Africa generally receive assistance from international donor agencies and NGOs in the industrialised countries of the North. This assistance takes the form of finance, equipment (e.g. vehicles), food and expert staff. The Copperbelt home care programme is no exception, relying on support from a consortium of European donor organisations for most of its annual budget.

Ideally, countries such as Zambia should be able to fund their health and development programmes from their own resources. The reality, however, is very different. The burden of Zambia's external debt – now standing at over $7 billion – severely restricts the funds available for services such as health and education. In 1997, for example, Zambia paid $324 million to service its external debt – twice its expenditure on health. Debt relief would enable countries such as Zambia to invest more money in their own health, education and economic development. In the immediate future, however, expanding community-based home care for people with HIV/AIDS and TB in Zambia and other countries in sub-Saharan Africa will require increased aid from the North.

Crisis management

In Zambia, as in many other African countries, the dual epidemic of HIV/AIDS and TB is tearing apart the social fabric of families and communities, and making impossible demands on health and social services that are already stretched beyond breaking point. Coping with the consequences of the dual epidemic calls for a long-term, concerted effort of crisis management, involving not only the health system but all sections and levels of government and society.

Crisis management, however, should not mean that precious resources are spent on hastily conceived projects which are poorly targeted and not cost-effective. Rather, it should mean choosing the most appropriate strategies for ensuring that people who are chronically ill with HIV/AIDS or TB – and their families – have access to a basic level of care and support. The strategy of community-based home care, combined with TB control using the DOTS strategy, has the potential to achieve this objective, even in low-income communities.

The community-based approach to home care, however, is more than simply a strategy for increasing the coverage of

Home care volunteers live and work with the people, "under the mupundu tree", and understand the human consequences of the dual epidemic of HIV/AIDS and TB.

health services and social support to people who are chronically ill with HIV/AIDS or TB. It represents, in effect, a long-term investment in precious human potential. By training and supporting volunteers, community-based home care helps to empower local people and communities with the knowledge, skills and self-confidence they need to cope with the impact of the dual epidemic of HIV/AIDS and TB.

In the final analysis, the home care volunteers themselves are the best guarantors of the long-term sustainability of home care programmes. They live "under the mupundu tree", close to the people and their problems, ready to respond to other people's needs with a simple, unselfish gesture of human kindness.

ADDITIONAL RESOURCE MATERIALS

MANUALS, HANDBOOKS & TRAINING PACKAGES

1. AIDS Home Care Handbook, by WHO/Global Programme on AIDS, Geneva, 1993. Available free of charge from the UNAIDS Information Centre, 20 avenue Appia, CH-1211 Geneva 27, Switzerland.

2. AIDS in Africa, 2nd edition, 1997. Available from Rapid Science Publishers, 2-6 Boundary Row, London SE1 8HN, UK.

3. AIDS in the World II, Jonathan Mann and Daniel Tarantola (eds.), Oxford University Press, New York, 1996. Available from Oxford University Press, 200 Madison Avenue, New York, NY 10016, USA.

4. Clinical Tuberculosis, by J. Crofton, N. Horne & F. Miller, Macmillans, 1992. Available from TALC, P.O. Box 49, St Albans, Herts AL1 5TX, U.K.

5. Confronting AIDS. Public Priorities in a Global Epidemic, published for the World Bank by Oxford University Press, New York, 1997. Available from Oxford University Press, 200 Madison Avenue, New York, NY 10016, USA.

6. Do We Care? The Cost and Quality of Community Home Based Care for HIV/AIDS Patients and their Communities in Zimbabwe, by G. Woelk et al, Harare, 1997. Available from SAfAIDS, P.O. Box A509, Avondale, Harare, Zimbabwe.

7. HIV prevention and AIDS care in Africa. A district level appraoch, by Japheth Ng'weshemi et al (eds.), Royal Tropical Institute, Amsterdam, 1997. Available from Royal Tropical Institute, P.O. Box 95001, 1090 HA Amsterdam, The Netherlands.

8. Sexual Health and Health Care: Care and Support for People with HIV/AIDS in Resource-Poor Settings, by Charles Gilks et al, Department for International Development (DFID), London, 1998. Available from DFID, 94 Victoria Street, London SW1E 5JL, UK.

9. TB/HIV – A Clinical Manual, by Anthony D. Harries and Dermot Maher, WHO, Geneva, 1996. Available from TALC, P.O. Box 49, St Albans, Herts AL1 5TX, U.K.

10. HIV/AIDS in Zambia. Background, Projections, Impacts, Interventions, Ministry of Health/Central Board of Health, Lusaka, December 1997. Available from Central Board of Health, Ndeke House, P.O. Box 32588, Lusaka, Zambia.

11. Treatment of Tuberculosis: Guidelines for National Programmes, WHO, 1997. Available from TALC, P.O. Box 49, St Albans, Herts AL1 5TX, U.K.

NEWSLETTERS, PAMPHLETS AND OTHER MATERIALS

1. AIDS Action. Free to readers in developing countries. Available from: Healthlink Worldwide, 29-35 Farringdon Road, London EC1M 3JB, U.K.

2. AIDS Analysis Africa. By subscription only. Available from: AIDS Analysis, Suite 71, Ludgate House, 107-111 Fleet Street, London EC4 2AB, U.K.

3. AIDS Newsletter. By subscription only. Available from: CAB International, Wallingford, Oxon OX10 8DE, U.K.

4. Alliance News. Free to readers in developing countries. Available from International HIV/AIDS Alliance, 2 Pentonville Road, London N1 9HF, U.K.

5. Care at home for patients with AIDS in resource-poor countries, Medical Mission Institute (MMI), Würzburg, 1998. Available free of charge from MMI, Salvatorstrasse 7, D-97074 Würzburg, Germany.

6. Living with AIDS in the Community, by WHO/Global Programme on AIDS, Geneva, 1992. Available free of charge from the UNAIDS Information Centre, 20 avenue Appia, CH-1211 Geneva 27, Switzerland.

7. Provision of Pharmaceuticals in Home-based Care Programmes, Medical Mission Institute (MMI), Würzburg, 1998. Available free of charge from MMI, Salvatorstrasse 7, D-97074 Würzburg, Germany.

8. SAfAIDS News. Available by subscription from SAfAIDS, P.O. Box A509, Avondale, Harare, Zimbabwe.

9. Sexual Health Exchange. Free to readers in developing countries. Available from: Library and Documentation Department, Royal Tropical Institute, P.O. Box 95001, 1090 HA Amsterdam, The Netherlands.

REFERENCES

1. UNAIDS/WHO, *Report on the Global HIV/AIDS Epidemic, June 1998.*

2. Ministry of Health/Central Board of Health, HIV/AIDS in Zambia: *Background, Projections, Impacts and Interventions*, December 1997.

3. Ibid.

4. Ibid.

5. Ibid.

6. Ibid.

7. Ibid.

8. See *From Fear to Hope* and *AIDS Management: an Integrated Approach*, nos. 1 and 3 respectively in the Strategies for Hope Series.

9. Ministry of Health, *Mid-term Review of the Second Medium Term Plan for the Prevention and Control of AIDS in Zambia*, January 1997.

10. World Health Organization and Zambian Ministry of Health, *Cost and Impact of Home-based Care for People Living with HIV/AIDS in Zambia*, 1994.

11. Ibid.

12. Ibid.

13. Ibid.

14. Ibid.

15. *SAfAIDS News*, June 1994.

16. Irene Veldhuizen and Piet Reijer, "Coverage of a community-based home care programme in Copperbelt Province, Zambia", unpublished report, May 1998.

17. Susan Foster, "Cost and burden of AIDS on the Zambian Health Care System: Policies to Mitigate the Impact on Health Services", John Snow Inc. and London School of Hygiene and Tropical Medicine, 1993 (mimeo).

18. Dermot Maher, Global Tuberculosis Programme, World Health Organisation, personal communication.

19. Originally published in English in Kenya by MAP International, the Christian Health Association of Kenya and the Institute for Development Training.

20. Ministry of Health/Central Board of Health, *HIV/AIDS in Zambia: Background, Projections, Impacts, Interventions*, December 1997.

21. Ibid.

THE STRATEGIES FOR HOPE SERIES

Most Strategies for Hope materials are also available in French, and some in Swahili and Portuguese. For details, please contact TALC (address on page 62), or visit our Web site: **www.stratshope.org**

BOOKS

1: FROM FEAR TO HOPE: AIDS Care and Prevention at Chikankata Hospital, Zambia – A rural hospital's home-based care programme for people with HIV/AIDS.

2: LIVING POSITIVELY WITH AIDS: The AIDS Support Organisation (TASO), Uganda – How TASO provides care, counselling and support for people with AIDS and their families.

3: AIDS MANAGEMENT: AN INTEGRATED APPROACH – The organisation and management of a comprehensive AIDS control and prevention programme by a rural hospital in Zambia.

4: MEETING AIDS WITH COMPASSION: AIDS Care and Prevention in Agomanya, Ghana – The work of a maternity clinic in AIDS prevention, and home-based care and support for people with AIDS. (English edition out of print.)

5: AIDS ORPHANS: A Community Perspective from Tanzania – The impact of AIDS on the family system in rural Tanzania, and community coping mechanisms.

6: THE CARING COMMUNITY: Coping with AIDS in urban Uganda – How members of a church in Kampala provide care, support and comfort to people with AIDS, and also promote safer sexual behaviour.

7: ALL AGAINST AIDS: The Copperbelt Health Education Project, Zambia – The first four years of an AIDS prevention project in Zambia's Copperbelt.

8: WORK AGAINST AIDS: Workplace-based AIDS Initiatives in Zimbabwe – Successful workplace-based AIDS programmes in urban and rural areas of Zimbabwe.

9: CANDLES OF HOPE: The AIDS Programme of the Thai Red Cross Society – How the Thai Red Cross provides information, care and support to people with HIV and AIDS.

10: FILLING THE GAPS: Care and Support for People with HIV/AIDS in Côte d'Ivoire – Institutional and community-based initiatives for coping with HIV and AIDS in Côte d'Ivoire.

11: BROADENING THE FRONT: NGO Responses to HIV and AIDS in India – Innovative responses to India's HIV epidemic by local development agencies, women's organisations. community groups and human rights organisations.

12: A COMMON CAUSE: Young people, sexuality, HIV and AIDS in three African countries – Case studies of sexuality education and HIV prevention programmes for young people in Botswana, Nigeria and Tanzania.

13: YOUTH-TO-YOUTH: HIV prevention and young people in Kenya – Youth-led HIV prevention initiatives among young people in urban and rural areas of Kenya.

14: UNDER THE MUPUNDU TREE: Volunteers in home care for people with HIV/AIDS and TB in Zambia's Copperbelt – How volunteers enable a home care programme to achieve high coverage of people with HIV/AIDS, and high TB cure rates, in low-income, urban communities. (See also VIDEOS below.)

VIDEOS

THE ORPHAN GENERATION: Community-based care and support for children orphaned by AIDS (50 minutes): The struggle of a Ugandan village community to cope with the deepening orphan crisis caused by the HIV/AIDS epidemic. Includes a 10-minute programme "These are our Children".

HIV/AIDS COUNSELLING: the TASO Experience (30 minutes): Training video for HIV/AIDS counsellors, based on the work of The AIDS Support Organisation (TASO) in Uganda. Note: this is a re-release of Part 2 of the video "TASO: Living Positively with AIDS" (1990).

UNDER THE MUPUNDU TREE: Community-based home care for people with HIV/AIDS and TB (40 minutes): How volunteers play a frontline role in HIV/AIDS care and support and TB control in low-income townships of Zambia's Copperbelt. (See also Book 14 above.)

TRAINING PACKAGE

STEPPING STONES – A 240-page training manual and a 70-minute workshop video on HIV/AIDS, gender issues, communication and relationship skills. Contains full instructions on how to run 60 hours of workshop sessions, divided into 18 sessions, over 10 to 12 weeks.

*** PLEASE SEE ORDER FORM ON THE REVERSE OF THIS PAGE ***

SPECIAL OFFER

Organisations based in sub-Saharan Africa that are unable to pay in foreign currency may request up to 3 copies each, free of charge, of Books 6 - 14 in the Strategies for Hope Series. Requests for larger quantities will also be considered, on receipt of an explanatory letter. These requests will be considered as long as stocks are available.

Organisations in Zimbabwe may purchase all Strategies for Hope Series books and the Stepping Stones training package, at greatly reduced rates in local currency, from the Grassroots Book Café, PO Box A267, Avondale, Harare.

ORDER FORM

		Price each	Quantity	Total £:
No. 1:	FROM FEAR TO HOPE (Zambia)	£2.50		
No. 2:	LIVING POSITIVELY WITH AIDS (Uganda)	£2.50		
No. 3:	AIDS MANAGEMENT (Zambia)	£2.50		
No. 4:	MEETING AIDS WITH COMPASSION (Ghana) Out of print	£2.50	-	-
No. 5:	AIDS ORPHANS (Tanzania)	£2.50		
No. 6:	THE CARING COMMUNITY (Uganda)	£2.50		
No. 7:	ALL AGAINST AIDS (Zambia)	£2.50		
No. 8:	WORK AGAINST AIDS (Zimbabwe)	£3.25		
No. 9:	CANDLES OF HOPE (Thailand)	£2.50		
No.10:	FILLING THE GAPS (Côte d'Ivoire)	£3.25		
No.11:	BROADENING THE FRONT (India)	£3.25		
No.12:	A COMMON CAUSE (Botsw/Nigeria/Tanz)	£3.25		
No.13:	YOUTH-TO-YOUTH (Kenya)	£3.25		
No.14:	UNDER THE MUPUNDU TREE (Zambia)	£3.50		

TOTAL (Prices include postage & packing worldwide): £

Please tick if you would like an order form for: Strategies for Hope Series videos ☐
Stepping Stones Training Package ☐

NAME: .....

ORGANISATION: .....
(Please do not abbreviate)

.....

ADDRESS: .....

.....

.....

PAYMENT:

- I enclose £.....
  (Please make cheques and money orders payable to TALC.) or:
- Please charge to my card:
  MASTERCARD/VISA

No: .....

Expiry date: .....

Name: .....

Signature: .....

FREE COPIES: *For details of how to request free copies of these books, please see page*

Please send this form, together with payment, to: **TALC, P.O. Box 49, St Alban**
Herts AL1 5TX, U.K. Fax: (44)1727 846852. E-mail: talcuk@btinternet.com

The **STRATEGIES FOR HOPE** Series aims to promote informed, positive thinking and practical action, by all sections of society, in responding to the challenges of HIV and AIDS.

A project of the British NGO, ActionAid, **STRATEGIES FOR HOPE** produces books and videos that document 'good practice' in HIV/AIDS work by NGOs and community-based organisations in developing countries, especially in sub-Saharan Africa.

The Series began in 1989 and has since produced fourteen books, three videos and a training package.

Series Editor: Glen Williams
Medical Adviser: Dr Nigel Padfield

THE AUTHORS

Petri Blinkhoff is a social scientist and consultant on health and development issues, based in Lusaka, Zambia.

Esaya Bukanga is a practitioner of theatre for development and coordinator of the HIV/AIDS prevention programme of Ndola Catholic Diocese, based in Ndola, Zambia.

Brigitte Syamalevwe is an educationist, community worker and trainer on health, development and gender issues, based in Ndola, Zambia.

Glen Williams is Editor of the Strategies for Hope Series, based in Oxford, UK.

TECHNICAL ADVISERS

Piet Reijer is Director of the AIDS Department, Ndola Catholic Diocese, Ndola, Zambia.

Dermot Maher is Medical Officer, Communicable Diseases, World Health Organization, Geneva, Switzerland.

ISBN 1 872502 53 9